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WORK INTERRUPTED: A QUESTIONNAIRE
ASSESSING THE RELATIONSHIP BETWEEN WORK-RELATED
DISTRESS AND PSYCHOLOGICAL ADJUSTMENT TO CANCER

A dissertation submitted to the Faculty of Antioch University
Santa Barbara in partial fulfillment of the requirements for the
Degree of Doctorate of Psychology in Clinical Psychology with
a Family Psychology specialization and a concentration in
Family Forensic Psychology

By

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Abstract

Cancer is an increasingly survivable disease that significantly impacts the ability of individuals to negotiate successfully the developmental task most distinctly affiliated with middle adulthood: creating meaning through achievement, creativity, and service. For many adults, these goals are accomplished through employment. When cancer intrudes, patients may be deprived of the ability to participate fully in the “generativity” that developmental psychologist Erik Erikson deemed essential to a healthy adulthood. In qualitative studies, patients’ narratives speak of many work-related losses — of routine, normality, economic stability, social connection, purpose, and identity. While psychosocial issues and quality of life are viewed with increasing importance within the literature on cancer, there appears to be a paucity of quantitative data on the work-related distress alluded to in these studies. Building on themes from qualitative literature and personal therapeutic encounters, a work distress survey was developed and administered to 74 adult patients treated for cancer at a community cancer center. A strong association was found between work-related distress and negative — but not positive — psychological adjustment to cancer. A cluster of items related to diminution of the *structural* functions of work — a means of organizing the day, staving off boredom, and providing individuals with a sense of

normality — were most strongly associated with negative psychological adjustment to cancer in this study. Implications for future research, clinical practice, and occupational application are discussed.

The electronic version of this dissertation is at OhioLink ETD Center, www.ohiolink.edu/etd

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Introduction

Cancer takes so profound an emotional toll on patients that distress has been proposed as the sixth vital sign, to be monitored and treated along with blood pressure, respiration, and pain (Bultz & Holland, 2005; Bultz & Holland, 2006; Holland and Bultz, 2007). Reflecting a growing recognition of the importance of distress among cancer patients, a fairly extensive literature has begun to emerge that qualitatively explores psychological adjustment throughout the cancer journey, from diagnosis through treatment and beyond, to the increasingly common and prolonged life stage of cancer survivorship. Within the literature, the impact of work-related loss (financial, social, structural, and existential) arises as a frequent theme in general, non-directed focus groups. A small number of qualitative studies in the U.S. and Europe have specifically focused on cancer and work, offering a more nuanced insight into the experiences of working adults diagnosed with cancer.

While qualitative studies are helpful in guiding research, quantitative research is needed to lend a more sophisticated and detailed perspective to these general findings. The relative contribution of work-related loss to overall distress will be important to understand as the psychosocial oncology community moves to integrate distress assessment and management into accepted protocols for cancer care. Further, quantitative research would help to determine whether the

issues raised by individuals in focus groups are relevant and widely applicable to adult cancer patients in a range of treatment settings. To be of practical use, psychologists and other mental health professionals must have a deeper understanding of work-related barriers to optimal quality of life and well-being. If these challenges can be better elucidated, it may be possible to develop screening tools, educational materials, and/or therapeutic strategies to identify and alleviate work-related distress associated with a cancer diagnosis.

This study explores, via a questionnaire, potential associations between multidimensional work-related distress experienced during and after cancer treatment and psychological adjustment to the disease.

Background and Rationale for the Study

Developmental psychoanalyst Erik H. Erikson famously quoted Sigmund Freud as characterizing the two necessities for a fulfilling life as “Lieben und arbeiten,” – “To love and to work.” (Erikson, 1963, p. 265). “Industry,” in fact, was dichotomized against “inferiority” in Erikson’s view of the development of a healthy personality and productive ego identity formation during childhood (Erikson, 1980, p. 87). In describing children from nursery-school age on, he wrote, “They all, sooner or later, become dissatisfied and disgruntled without a sense of being useful, without a

sense of being able to make things and make them well and even perfectly; this is what I call the *sense of industry*” (Erikson, 1980, p. 91).

The theme of industry, first associated with children’s burgeoning sense of independence, self-worth, and initiative, continues throughout an individual’s life, re-emerging as a predominant focus in Erikson’s depiction of middle adulthood, the seventh stage of development. Within this stage, conceptualized as an individual’s cultivation of “*generativity*, versus self-absorption and stagnation,” Erikson defined the highest virtue as caring, as opposed to being *cared for* (1982, p. 67). In middle adulthood, then, he saw as essential tasks meaning-making through production, creativity, and service. To these, he added mentoring, an imparting of “strength in the next generation” (p. 67). Productivity and passing on of the fruits of one’s worth were seen by Erikson as critically essential to identity in middle life, as was the passing on of one’s genes (procreativity) and life lessons through parenthood (Erikson, 1980, p. 103). In his words, “Mature man needs to be needed,” (Erikson, 1963, pp. 266-267).

Although generativity can apply to the building of a solid social foundation of friends, family, and home, it is through work during this life stage that many adults cement the financial underpinning on which their families’ futures will depend. They may advance in their careers, switch careers, build their businesses, hone their skills, and begin to mentor others. Drawing on years of preparation, they may feel a true sense of competency and discovery in their life work, essentially sharing the fruits of their labor with less experienced workers or society as a whole. After decades of

development that depend on taking from others, the generativity stage is a time for nurturing, creating, and giving (Erikson, 1963; Fouad & Bynner, 2008).

In Western societies, work has taken on a particularly pivotal role in the adult lives of individuals as well as in communities (Fryers, 2006; Peterson, et al., 2000). This imperative in Western culture can be traced historically to the era of the Protestant Reformation (1517-1648), marked by Martin Luther's emphasis on vocation (a word derived from the Latin, *voco*, to call), as a duty to be performed in a manner that pleases God (Bunderson, J. S. & Thompson, J. A., in press). German sociologist and political economist Max Weber (1864-1920) first extrapolated the significance of Luther's philosophy on modern work and capitalism, highlighting Luther's belief that *all* legitimate and well-pursued "callings" earned equal spiritual dignity, as opposed to the Catholic belief that the monastic life was spiritually superior to pursuits in common industry (Weber, 2001 translation, pp 40-41). John Calvin, the French/Swiss theologian, incorporated predetermination into how work was viewed in the late 16th Century, since how one performed one's earthly duties was seen as a window into one's fate, with hardworking, successful people deemed destined to be chosen by God. Over time, the work ethic became secularized, yet a powerful sense of duty remains inherent in the "goodness" of a person who is tireless, self-reliant, and adept in his or her occupational pursuits. In Weber's own words, "... the idea of duty in one's calling prowls about in our lives like the ghost of dead religious beliefs" (Weber, p. 124).

The importance of work is a common theme running through classical literature, evidenced by a moral lesson voiced by the Turk, in satirist Voltaire's *Candide: On Optimism* (1759, reprinted, 2009, p. 92): "Our work keeps at bay the three great evils: boredom, vice, necessity." Beyond "necessity" — the obvious financial incentive of having a job — heroes in Western cultures are portrayed as devoted to professional lives infused by undercurrents of righteousness, duty, dignity, and worth (Tournier, 1972). Although some of the overt religious significance of work may have been minimized in modern times, work in the Western world today fulfills broad roles for the individual, providing a sense of purpose, self-esteem, personal identity, status, belonging, daily structure, and a variety of social interactions, including friendships (Peteet, 2000; Fryers, 2006). For many, work continues to give life its meaning; more than a job or career, it becomes a calling (Wrzesniewski, 1997; Bunderson & Thompson, in press).

For 1.5 million U.S. adults each year (American Cancer Society, 2010), into this milieu comes a seemingly premature reminder of the fleeting impermanence of the busy, task-oriented production of middle life. A nagging symptom or a routine medical appointment launches a dizzying journey that ends in the word, "malignant." Among adults ages 35-44, cancer represents the 2nd leading cause of death, edging out accidents to become the leading cause of death for individuals in their mid-40s to mid-60s (Centers for Disease Control and Prevention, 2004). By age 45 to 65, cancer incidence doubles, with another doubling in incidence rates for individuals over 65

(NCI SEER Program Data, 1994-1998). Among these adult cancer patients is a rapidly increasing population of people who live at least 5 years (and sometimes many more) beyond diagnosis. Today in the U.S., there are more than 10 million survivors of cancer, a tripling since 1971. (Institute of Medicine, 2005, p. 25) While active treatment and its side effects often interrupt employment, many cancer patients return to work. In 2002, the National Cancer Institute estimated that the workforce included 3.8 million working-aged adults (ages 20-65) who had returned to work, having survived cancer (Institute of Medicine, 2005).

Modern treatments allow some patients to continue to work throughout cancer treatment, at least part-time. However, some patients are unable to maintain employment and later find themselves physically or logistically unable to continue their occupational pursuits. They may be subject to workplace discrimination, including being passed over for promotions or transferred to undesirable positions (Institute of Medicine, 2005). The job hunt for a cancer survivor is a challenging one, since many potential employers fear they will miss work days or cost the company exorbitantly in terms of benefits (Institute of Medicine, p. 364). Federal law does protect cancer survivors to some degree, but subtle unfair practices continue, undermining survivors' financial security, professional esteem, and potential for accomplishment (Institute of Medicine, p. 365).

Recent studies show variable rates of work participation following a diagnosis of cancer. Short, Vasey, & Tunceli (2004) found that 13% of 1,433 survivors quit

working following a diagnosis of cancer, most within a year. While 92 of 100 survivors in one cancer registry returned to work, 57% reduced their work by more than 4 hours/week and 56% described changes in their occupational roles, such as reducing their overtime hours or extra work responsibilities (Steiner, Cavender, Nowels, Beaty, Bradley, Fairclough, & Main, 2008).

The sense of work-related distress described by cancer patients is an evolving construct within psycho-oncologic literature; however, clinicians in practice encounter it frequently (T. Deshields, personal communication, October 23, 2009; M. Solis, personal communication, May 12, 2010; D. Morrison, personal communication, October 20, 2011). At one community cancer center, work issues often arise as a topic of concern during a twice-monthly support group for cancer patients and their families. As a co-facilitator of this group, the author noted that patients became emotional about the losses suffered as a result of their necessary work absences or cancer-related retirements. Tears filled the eyes of an elementary school teacher who described telling her 2nd graders that another teacher would be taking over the class for the rest of the year. She explained that the lesson plans and materials she left behind for the substitute had represented her passion for teaching, symbolic of her life's accomplishments. She said that without looking forward to standing in front of the classroom each day, she felt "lost." An engineer in his 70s has described his "stubbornness" in staying on the job whenever possible despite his illness, since that is what makes him feel normal and productive.

Other patients described emotional setbacks as a result of the response they received at work when they announced they had cancer. One man who said he devoted his life to his job described a sense of betrayal when his supervisor of many years, a man he considered a friend, responded angrily, seemingly more concerned about how deadlines would be met than about the patient's well-being. In several cases, patients recalled employers calling them with work-related demands while they were hospitalized following surgery or receiving chemotherapy.

More than one patient described having an epiphany about work following a cancer diagnosis. A man who described himself as a "workaholic" said he worked seven days a week for his entire adult life and announced his intention to now explore other important aspects of his life. His zeal for fully living a life outside work caused marital strain. His wife did not share his new interest in traveling throughout the U.S. and spending more time with their grown children.

Patients also shared their financial concerns in the wake of a cancer diagnosis, when medical bills piled up as job security seemed most uncertain. Many who had been forced to leave their employment due to long-term effects of their cancer expressed profound distress and a sense of guilt that they would be letting their families down. One woman who temporarily could not work looked at the totals of her bills and despaired, "I wonder if I'm even worth it."

In analyses of formal focus groups and other qualitative studies, similar themes arise. Frequently mentioned elements of work-related distress in interviews

with cancer patients include structural loss of routine and “normalcy” (Amir, Neary, & Luker, 2008; Coyle, 2006; Filipp, 1992; Fryers, 2006; Kennedy, Haslam, Munir, & Pryce, 2006; Main, 2005; Parsons, Eakin, Bell, Franche, Davis, McFadden, & Carone, 2008; Rasmussen & Elverdam, 2008), financial instability (Amir, Neary, & Luker, 2008; Fryers, 2006; Kennedy, Haslam, Munir, & Pryce, 2006; Main, Nowels, Cavender, Etschmaier, & Steiner, 2005; Parsons, Eakin, Bell, Franche, & Davis, 2008; Steiner, Cavender, Nowels, Beaty, Bradley, & Fairclough, 2008), a loss of social connectedness (Amir, Neary, & Luker, 2008; Costanzo, Ryff, & Singer, 2009), and a diminishment of one’s sense of purpose and identity (Main, Nowels, Cavender, Etschmaier, & Steiner, 2005; Parsons, Eakin, Bell, Franche, & Davis, 2008). No standardized psychometric scales exist to consistently and reliably measure distress associated with these personal and professional losses. However, observational experience and a thorough review of the literature reveal that this is an important concept within the context of cancer survival. It is a theme that frequently emerges in discussions about psychological adjustment to a disease that often strikes at a time when work is an important source of structure, identity, and social interaction.

The current study aims to further psychosocial research in the area of work-related losses and distress within the larger context of psychological adjustment to cancer, and to begin to focus on which facets of work-related loss may be most relevant to recently treated adult cancer patients.

Research Questions

1. Is work-related distress independently associated with psychological adjustment to cancer among adults?
2. Do specific components of work-related distress (existential, structural, social, and/or lack of work-related support) exert distinct and independent influences on psychological adjustment to cancer?

Hypotheses

1. Higher levels of work-related distress among adult cancer patients predict lower positive mental adjustment to cancer when controlling for age, sex, education, cancer type and stage, functional impact of disease, employment category, magnitude of employment loss, and work orientation.
2. Higher levels of work-related distress among adult cancer patients predict higher negative mental adjustment to cancer when controlling for age, sex, education, cancer type and stage, physical impact of disease, employment category, magnitude of employment loss, and work orientation.
3. Specific components of work-related distress (structural, social, and existential distress, and the lack of work-related support) differentially correlate with positive and negative mental

adjustment to cancer, when controlling for age, sex, education, cancer type and stage, physical impact of disease, employment category, magnitude of employment loss, work orientation, and work-related support.

Review of the Literature

In his commentary, “Cancer and the Meaning of Work,” Dr. John R. Peteet, director of the adult psychosocial oncology program at Dana-Farber Partners Cancer Care at Harvard University, notes that much research on cancer and work has focused on patients’ employability and ability to perform at their previous jobs. What these studies fail to consider is what Peteet calls “work-related distress,” the fraying of one’s work-related self-concept and sense of meaning via “core values, such as creating new knowledge, contributing to society, or providing for one’s own” (Peteet, 2000, p. 204).

Peteet’s (2000) own interviews with cancer patients found evidence of crises of self-esteem, a relinquishment of structure and predictability, despair over discrimination, and a “trauma of losses” —financial, social, and existential —as a result of employment disruption due to the disease. He called for a better screening tool to assess work-related distress in the areas of identity, normalcy, and fairness (Peteet, p. 203).

Other domains of work-related loss and more specific exploration into their resulting psychological sequelae may identify important barriers to cancer adjustment that potentially could be addressed with preventive measures, psychoeducation, work-specific interventions, and/or employer training. For example, the disruption of work was cited as one of a number of factors contributing to purposelessness, understimulation, and boredom in cancer patients in an initial validation of a scale measuring aspects of adjustment that are sometimes overlooked in studies of depression and quality of life (Passik, Eakin, Bell, Franche & Davis, 2008). Tellingly, this finding emerged even though patients in that study had retired before the diagnosis of cancer and not a single question directly addressed work issues.

The seeming lack of attention to the role of work in cancer distress and recovery is not surprising. Blustein (2008) has charged that the role of work in people's lives has largely been "compartmentalized" or "marginalized" within the field of psychology as a whole, with the preponderance of research generally reflecting the perspectives of employers through industrial, organizational, and rehabilitation psychologists (p. 228). What is missing with this focus is an understanding of the contributions of work to "natural human strivings for survival, relational connections, and self-determination" (Blustein, 2008, p. 237) and, importantly, the psychological consequences experienced when work is interrupted due to a layoff, firing, or illness such as cancer. A number of researchers have called for more investigation into the area of work and meaning, many specifically

highlighting the need for more study about work loss in the context of cancer (Amir et al., 2008; Blustein, 2008; Foley et al., 2006; Mahar et al., 2008; Main et al., 2005; Parsons et al., 2008; Peteet, 2000; & Rasmussen & Elverdam, 2008). Thus far, work has been discussed by cancer patients during qualitative studies about cancer adjustment (Foley et al., 2006; Peteet, 2000), and has been the specific focus of other qualitative studies (Amir et al., 2008; Kennedy et al., 2006; Main et al., 2005; Parsons et al., 2008; Rasmussen & Elverdam, 2008). A number of surveys have explored whether or not cancer survivors returned to work, and analyzed their reasons, which included personal as well as financial considerations (Liu, 2008; Mahar et al., 2008; Short et al., 2005; Steiner et al., 2008).

Qualitative studies have, for many years, collected information from patients undergoing active cancer treatment and survivors in remission. These studies have often elicited unprompted impressions about changes in work status and the impact this has had on cancer survivors. In addition, some qualitative studies have specifically probed for insights into this aspect of adjustment to cancer and cancer treatments.

Structural Work Themes: Normality, Engagement, Security

Across a number of studies, the theme of work as a sign of “normality” emerged. A yearning for the routine associated with working life was linked to adjustment in a qualitative study of 29 cancer survivors (Kennedy, Haslam, Munir, & Price, 2006). Closely related sentiments emerged in a study of 41 cancer survivors in

the U.K., who cited the “quest for normality” as a central motivator for return to work (Amir, Neary, & Luker, 2008, p. 190). Similarly, Rasmussen and Elverdam (2008) found that among 26 successfully treated Danish cancer survivors, work was commonly described as a “natural” part of life that brings structure and order to one’s days (p. 1234). In this study, as in the others, a return to work was highly sought after, representing to many patients a milestone symbolizing that they were healthy and normal once again. The personal meaning of work’s function as a proof of health and “normal life” was illustrated in comments recounted in a qualitative study by Main et al., 2005. In this study, one patient said that maintaining a work schedule reassured her daughter that she was not desperately ill. On the other hand, Rasmussen and Elverdam (2008) found that the anticipated return to a sense of “normal” life upon resumption of work came as a disappointment to some Danish patients who participated in their qualitative study. These individuals described a sense of defeat when they realized they were still not “normal” (p. 1234) despite the familiar surroundings and rhythm of a working life.

Boredom is also a prominent theme raised by cancer survivors in the literature on work outcomes, with work often characterized as a return to purposeful engagement in life (Amir et al., 2008; Freyers, 2006; Kennedy et al., 2006; Main et al., 2005; Steiner et al., 2004). In a meta-analysis of 18 qualitative studies, tedium and a sense of uselessness were associated with a loss of work hours and change in occupational role (Steiner et al., 2004). Main and colleagues also found that work

served as a distraction from the fear and discomfort associated with cancer and its treatment. As one survivor in their study remarked, “A good part of getting back to work is that it’s a non-cancer thing. You forget about whatever else you’re doing. It’s not a support group. It’s not acupuncture; it’s not your appointments. It’s something totally away from cancer,” (p. 997).

Not unexpectedly, studies on cancer patients and survivors frequently focused on employment’s central role as a source of financial security for patients and their families. A meta-analysis of nine qualitative studies identified financial concerns as one of seven recurrent themes in patient’s narratives (Steiner, Nowels, & Main, 2010). Researchers commonly found that a loss of income and financial security became acute sources of distress to patients as treatments became rigorous or their disease progressed (e.g., Amir, Neary & Luker, 2008; Coyle, 2006; Foley et al, 2006).

Themes Related to the Social Function of Work

Maintaining work friendships was an important source of support mentioned by participants in a number of qualitative studies (Amir, Neary, & Luker, 2008; Blustein, 2008; Costanzo, et al., 2009; Foley et al., 2006; Fryers, 2006; Main, Nowels, Cavender, Etschmaier, & Steiner, 2005; Rasmussen & Elverdam, 2008; Parsons, Eakin, Bell, Franche, & Davis, 2008). Loneliness and isolation set in for some patients when their work lives were interrupted by cancer. They expressed sadness over the loss of companionship and a sense of being a part of a social network. As one patient noted in a study by Main, et al. (2005): “My job has been I

think the hardest thing that I struggle with because I love to work and I love to, you know, be out and I miss not seeing my friends all the time” (p. 998).

Just as a failure to return to work dashed hopes of a restored sense of normalcy for some cancer patients, the workplace as a focus of anticipated social support held emotional pitfalls for others. A qualitative study of 41 cancer survivors in the U.K. (Amir, Neary, & Luker, 2008) found that those who did not receive meaningful contact with coworkers during treatment harbored resentment and described return-to-work adjustment difficulties. Rasmussen and Elverdam (2008) heard from Danish cancer survivors that some had faced frustrated reactions from coworkers when they returned to work post-treatment with emotional and physical sequelae (pain, fatigue, neuropathy, memory loss, incontinence) that interfered with their work performance.

Existential Themes: Work as a Source of Power, Identity, and Meaning

While work served as a means of making a living, filling one's days, and providing a social sense of community to patients interviewed in qualitative studies, deeper philosophical themes were in evidence throughout the literature as well. Amir, Neary, and Luker (2008) identified identity restoration as a driving motivator to some patients in their quest to return to work. One such patient in their study, a woman in her late 40s who had worked as a management accountant prior to her diagnosis with colon cancer, summarized this imperative thusly: “I know it's awful, but you feel as though you've lost your identity somehow... You feel as though you've lost part of

yourself, you know what I mean? You aren't the same person any more. I know work shouldn't mean that much to you, I suppose, but it does," (p. 193).

Similar themes resonated in other studies in which work loss represented to patients a slipping away of their sense of control, personal agency, power, value, a "place in the world" (Coyle, 2006), and individual identity (Fryers, 2006; Fouad & Brenner, 2008; Main et al., 2005; Parsons et al., 2008; Steiner, et al., 2008).

Coyle (2006) characterized a related theme as well: the particular struggle of patients to maintain their identities against the "anonymity of being just a case, a disease, or a statistical probability" (p. 269). In this quest, a terminal diagnosis heightened the urgency with which patients viewed the need to create a personal legacy, to leave a meaningful accomplishment behind or to touch the lives of those who might carry on their work. The literature detailed the connection between work and the existential human need to establish meaning and purpose in life. This theme echoed in the words of cancer patients who faced an uncertain future as well as those who successfully returned to work (Blustein, 2008; Foley et al., 2006; Fryers, 2006; Main et al., 2005; and Parsons et al., 2003).

Yet another common existential theme established in the literature on work and cancer was the evolution of perspective among patients who faced a threat to their survival. Foley et al. (2006), identified an almost spiritual theme of personal growth that underscored many patients' dialogues about their cancer journeys. The patients in this and other studies (Amir et al., 2008; Costanzo et al., 2009; Coyle,

2006; Fryers, 2006; Parsons et al., 2008; Steiner et al., 2008; Rasmussen & Elverdam, 2008) described quitting stressful jobs, changing jobs, and refocusing their priorities to place personal relationships over work.

Related themes emerged in a qualitative study by Main et al. (2005). In this study, one participant expressed the belief that work-related stress was the source of his cancer diagnosis, and many, especially men, said they rethought their life-work balance and life priorities following their cancer diagnosis. On the other hand, many said work brought “meaning, challenge, and accomplishment” to their lives post-cancer, at a particularly vulnerable emotional time. As one 45-year-old survivor stated:

I totally reviewed things that I determined were important in my life, so that I could devote what energy I could to those things and let the rest of it go. ... I like my work and I'm employing people that are very important to me...but work is just work. This is not finding a cure for cancer. If I didn't work tomorrow, if this company didn't exist, the world would hardly notice. So, keeping it in perspective. It's just a job. (p. 1001).

Support: Seeking Work-Specific Guidance and Understanding

Cancer patients' need for guidance, empathy, and work-specific support from employers and health professionals was a highly consistent theme threaded throughout the literature on work and cancer. In many studies, patients voiced regrets that more of this type of assistance was not forthcoming (Amir et al., 2008; Fryers,

2006; Kennedy et al., 2007; Main et al., 2003; Parsons et al., 2003; & Steiner et al., 2008).

Specifically, many patients expressed the wish that they had received more direction from their health professionals about when to cut back on work during treatment and when to return to work on a part-time or full-time basis. In the qualitative study by Main et al. (2005), patients actually described conflicts with physicians about a return to work (p. 998). One physician reportedly pressured an individual on disability to return because, "People do better when they work." Another told a bored patient she would be better off at home than winding up in the hospital (suggesting that her desire to return to work would adversely impact her health).

A related recurrent theme centered on how patients perceived employers' responses to challenges associated with their disease. Fatigue, memory problems, anxiety, depression, and multiple physical limitations were seen as barriers to some who wished they could return to work (Kennedy, 2007; Main, Nowels, Cavender, Etschmaier, & Steiner, 2005; Rasmussen & Elverdam, 2008). Patients recounted responses from the workplace, both supportive and unsupportive, in discussing their struggles with the enduring toll of their disease. Fryers (2006) characterized certification of disability in such cases as a particularly Western manifestation of the sense that work intrinsically defines individuals, and that its loss is in some ways seen as shameful and undignified.

When employers were supportive, flexible, and accommodating of their physical and emotional needs, patients reported an easier transition back to work (Kennedy, 2007). Patients frequently expressed gratitude to employers and coworkers alike when such conditions existed. However, when they perceived pressure or coercion to return to work or return to full function before they were physically capable of doing so, patients expressed resentment, a sense of betrayal, and frustration (Kennedy, 2007). It was further noted that mixed feelings among patients about their desire to be normal and yet their desire for accommodation might make it difficult for employers to fully meet the needs of employees with cancer. “An important paradoxical feeling about returning to work was raised in one of the focus groups; individuals agreed that they wanted to be treated normally at work, did not want to be labeled as a cancer patient, but they also felt that they needed some support or allowances” (p. 23).

Such allowances may, in some cases, need to be considerable. Persistent pain and permanent physical disabilities following cancer treatment, as well as psychological discomfort about alterations in physical appearance were the primary reasons cited by head and neck cancer patients for changing their jobs in a study conducted in Taiwan (Liu, 2007). In a telephone survey of 1,433 U.S. cancer survivors, one in five reported enduring disability that limited their ability to work one to five years post-diagnosis (Short, Vasey, & Tuneli, 2004). A total of 13% quit working due to their cancer in this study, the majority within the first

year after diagnosis. Of note, late-stage, central nervous system, and head and neck cancers were more likely to interfere with a return to work, theorized by the authors to reflect a higher level of overall disability. Especially challenging were problems relating to perception, cognition, and movement (p. 1300), speech difficulties, and profound changes in appearance due to surgery (Short, Vasey & Tuneli, 2004).

Psychological symptoms, including fears, boredom, anxiety, depression, and a sense of uselessness, also were prominent in cancer survivors in the two years following diagnosis, and associated with a loss of work hours and change in occupational role (Steiner et al., 2007). The impact of such symptoms is not as well-assessed as the impact of physical symptoms, and has been suggested as a focus of attention by clinicians for evaluation and possible treatment or referral.

Demographic Differences in Work-Related Experiences of Cancer Patients

Some domains of work-related loss may be age-specific. Findings from the Midlife in the United States (MIDUS) longitudinal national survey of health and well-being found long-term differences in psychosocial functioning of cancer survivors in comparison to age, gender, and education-matched controls, but these differences were limited to younger survivors (Costanzo, et al., 2009). This study of 398 cancer survivors, some diagnosed during the 11-year span of the survey, and 796 controls, provides some evidence in support of the idea that cancer compromises psychosocial functioning, with decrements seen in overall mental

health, mood, anxiety, environmental mastery, relationships with others, and self-acceptance. Signs of resilience were seen as well, however; with robust functioning in social well-being, spirituality, and personal growth lending credence to the concept that traumatic life events may foster posttraumatic growth. Although the study did not explore the issue of work, it does raise intriguing questions about the context of life events within the developmental lifespan. Subjects ranged in age from 25 to 74 at entry into Wave 1 of the study and 34 to 84 at the onset of Wave 2. Older survivors fared far better on virtually every measure of psychosocial adjustment and resiliency than did their younger counterparts. Compared to matched peers without a history of cancer, younger survivors had statistically significantly higher rates of depression and anxiety and lower positive affect and social actualization (the sense that society is improving for oneself and others). Trends in group differences – though not statistically significant — also were seen for positive relations with others, self-acceptance, and social integration, again with older survivors showing higher levels of psychological well-being than younger survivors.

Finally, the longitudinal study design of MIDUS permitted comparisons of psychosocial functioning prior to, and following the diagnosis of cancer in a subgroup of 207 individuals. Analyses of results in this subgroup unexpectedly found poorer psychosocial functioning on many measures prior to the diagnosis of cancer, raising questions about whether emotional vulnerability may have been

linked in some way (perhaps through lifestyle choices) to a subsequent cancer diagnosis, or whether psychological signs of cancer may have predated a physical diagnosis of existing disease. Again, however, age-related differences were seen, with younger survivors showing a much greater pre-diagnosis to post-diagnosis decline in psychosocial measures than older survivors, suggesting that their distress was more closely related to the diagnosis than their pre-existing functioning or outlook.

The timing of major life events has been theorized by developmental psychologists to impact adjustment, with experiences either conforming to expectations of individuals and society as “on time,” or falling outside the expected norms — “off time” (Filipp, 2002; Neugarten, 1968). Neugarten (1979) described individuals as gauging their lives according to a “mental clock” (p. 888) marked by appropriately timed life events such as marriage, childbearing, and culmination of one’s professional goals. So entrenched is this societal belief that it is subject of the much-quoted Bible verse 1 Ecc. 3:1-2 (King James version), “To every thing there is a season and a time to every purpose under the heaven: A time to be born, and a time to die.” Even when major life events represent losses (children leaving home, retirement, the loss of one’s parents or a spouse), they are not likely to provoke crises in adjustment if they occur “on time.” Since they are anticipated and prepared for — “the grief work completed” (Neugarten, p. 889) — they are seen ultimately as part of the bittersweet rhythm of life.

According to this school of thought, a cancer diagnosis during young adulthood or early middle age might be experienced as more shocking and perceived as more unfair — “Why Me?” — than would a life-threatening diagnosis later in life. Filipp (2002) stressed that an “off-time” cancer diagnosis interrupts the sequence of developmental tasks (such as work or raising a family), as opposed to the same diagnosis late in life, when serious illness is expected and may be considered a normative developmental challenge of advanced age.

The Literature as it Informs This Study

With the findings in these studies as a structural guide, the time has come to move beyond the preliminary foundation of qualitative research into the quantitative exploration of the meaning of work loss to individuals with cancer: specifically, through a questionnaire using themes derived from the existing literature.

Method

The purpose of this study was to survey adults recently treated for cancer about work-related losses they may have experienced during treatment and/or as the disease has progressed. Specifically, the study aimed at determining whether work-related distress in general and specific domains of work-related distress correlated with psychological adjustment to cancer in an adult patient population.

The design (see Figure 1) was constructed to control for important factors that might independently impact psychological adjustment to cancer, such as age, sex, education, cancer type, stage of disease, impact on physical functioning, and also to account for individual variation in issues related to work: employment category, magnitude of work loss during cancer treatment, and work orientation.

A questionnaire was distributed to patients who received treatment at a non-profit community cancer center to explore whether work distress predicts positive or negative psychological adjustment to cancer, and, if so, what type of distress is most salient to adjustment, with the aim of adding to exploratory literature on work and cancer.

Development of the questionnaire

To be useful, a screening questionnaire exploring work-related loss due to cancer must capture common work- and generativity-related themes across a diverse population, reflecting the opinions and beliefs of many groups of adult cancer patients, including those who are actively suffering from treatment- and disease-related symptoms; those in remission; those who may be pondering the realities of their employment potential as well as the role they want work to play in their lives; those with profound financial issues surrounding work; and those whose concerns are more existential, related to a narrowing of one's generativity goals and a heightened sense of mortality.

The author's personal observations of work-related discussions among cancer survivors in a community support group formed the initial impetus for the study. Within that setting, certain recurring themes of work-related loss were noted. In order to ensure that the questionnaire drew on a large body of evidence and was reflective of a broad population of cancer survivors, the literature on cancer and work was searched and coded by theme by the author. Specifically, PsycINFO, a database of psychological literature, and PubMed, the database of the U.S. National Library of Medicine, were searched using terms "work," "working," "employment," "generativity," "boredom," "cancer," "oncology," "survivor," "survivorship," "quality of life," "psychosocial," "psychological," "mental," "adjustment," and "distress." When pertinent studies were located, their references were used to locate further references of interest. In total, 33 journal articles or books were located that directly related to issues of work and psychosocial adjustment of cancer patients (see References). Qualitative studies in which cancer patients specifically discussed work-related psychological stressors were analyzed and organized according to themes of loss. It was at this point that the author noted that many of these themes fit well into a schema of work-related loss described by Rasmussen and Elverdam (2008). These Dutch researchers extensively interviewed 23 cancer survivors about the meaning work held after diagnosis, ultimately describing three distinct domains of loss, or distress: **structural** (expressed within qualitative studies as "normality," a reason to get up

in the morning, distraction, and healthy participation in life); **social** (connections with peers, participating in shared tasks, engagement with others); and **existential** (expressed in interviews as personal identity, pride, purpose, and legacy-building). A fourth component of work-related distress noted in the literature and personal observations was a **lack of support specific to employment**; that is, guidance on sick leave, disability, return to work, and fair treatment by employers during such transitions (Amir, et al., 2008; Fryers, 2006; Kennedy, 2007; Main, et al., 2005; Parsons, et al., 2003; Steiner, et al., 2008). Specific statements and general themes drawn from cancer support group observations and qualitative studies were therefore organized within these domains and used to construct original survey items reflective of distress expressed by cancer patients within the following domains: structural (Figure 2); social (Figure 3), existential (Figure 4), and lack of work-related support (Figure 5).

Many of the themes of loss reflected in these patterns of responses closely reflect Erikson's concept of the seventh psychosocial stage of life, *Care* (1963). This developmental stage, defined as occurring roughly between 35 and 65 years old, was seen by Erikson as a period of generativity or stagnation. In the ideal, he conceptualized this time as one of production, mentoring, and creativity in the context of contributing to society and establishing a legacy. As such, Erikson saw this as an externally focused stage of life within a well-adjusted adult, as opposed to the self-absorption one would see in an individual failing to progress healthily

through this time. With this in mind, cancer patients' descriptions of changes in their work lives may reflect frustration at seeing their potential for generativity replaced by stagnation – not by choice, but imposed upon them by a life-threatening disease. Transitioning quite suddenly from being a useful, competent contributor to society to being a patient who cannot work may disrupt not only the structure of one's life in middle adulthood but also one's existential view of self and the future. The social dimension within the questionnaire targeted the relatedness element of human adjustment, which should be quite well established by middle-adulthood and may prove to be quite centered in the environment where most people spend 40 hours a week or more: their jobs.

Questions addressing financial security, discrimination, and self-perception of physical capabilities were included because of the impact they could exert on psychological well-being, particularly among people whose limited resources may be quickly depleted by cancer. A lie scale also was included, incorporating two questions to assess any compromises to validity that may occur due to respondents' attempts to provide socially desirable answers rather than their genuine beliefs about the impact of work loss on their current lives. The study design attempted to adjust for potentially important variables such as the degree of work loss experienced by a patient (i.e., hours, full-time/part-time status); age; severity of illness; work-related support from health professionals, employers, coworkers, and family members; work orientation; and occupational

type.

Designed as a questionnaire, the instrument was investigational and broadly focused, in the hope that significant responses would highlight important clusters of work-related themes to be considered in the future development of a reliable, valid scale to identify cancer patients who are struggling with work identity issues.

Choice of Instruments and Selection of Covariates

An important potential confounder of any assessment of work involvement or psychological adjustment with regard to work-related loss is the degree to which one's physical symptoms might interfere with current and future ability to work, as well as one's ability or desire to focus on work-related goals and beliefs. Simply stated, a person suffering extreme symptoms from cancer treatment or from progression of his or her disease would be unlikely to be working, contemplating working, or thinking about the meaning of work in one's life. Many inventories exist to assess the severity of cancer symptoms and their impact on function. However, a review of cancer assessment instruments by Kirkova, et al. (2006), found that most such instruments include both psychological and physical symptoms, and often "distress" ratings as well, making them inappropriate for use as an independent variable intended to assess a strictly physical characteristic: severity of illness. (Type of cancer and stage at the

time of completion of the questionnaire partially address the issue of physical distress/debilitation, but not entirely, since people with Stage IV disease may have very different degrees of disability and physical discomfort.) Obviously, any instrument that includes “distress” in its symptom inventory cannot be used as an independent variable in a study whose dependent variable is “cancer-related distress.”

To avoid these difficulties, performance status rather than symptom severity was used (in addition to cancer stage) to control for disease-related severity variables that would be likely to preclude attention to work-related issues or distress. The Eastern Cooperative Oncology Group (ECOG) Performance Status scale by Oken, Creech, Tormey, Horton, Davis, McFadden, & Carbone (1982) is among the most widely used instruments to assess function and quality of life in the context of cancer (Buccheri, Ferrigno, & Tamburini, 1996). Its simple quantification of physical function relies on a graded scale of 0 to 4, with responses ranging from a fully active lifestyle, including ability to perform work tasks, to complete disability, marked by a bedridden status and inability to perform self-care. First published in 1982, the ECOG Performance Status scale was found by Conill, Verger, and Salamero (1990) to be valid and reliable among physicians (Kendall’s correlation 0.75), and between physicians and patients (Kendall’s correlation 0.59). More recently, Buccheri et al. (1996) and Blagden, Charman, Sharples, Magee, and Gilligan (2003) validated ECOG performance

scores as a highly reliable marker of prognosis after adjustment for sex and stage of disease.

Another important variable to consider in assessing the impact of work loss on an individual is that person's essential perspective on the role of work in the context of life and life satisfaction. To account for differences in this perspective, a 10-item work orientation scale was used to distinguish between perceptions of one's work as a job, a career, or a calling. These items, drawn from the University of Pennsylvania Work-Life Questionnaire, were found to strongly correlate with more elaborate paragraphs describing three distinctly separate viewpoints regarding the position of work within one's life perspective ($r = 0.40$ to 0.55 , $< .05$). These true-false items were selected from 18 within the original questionnaire as representing factors that had the highest eigen values in a principal components factor analysis of the matrix of intercorrelations, together accounting for more than 55% of the variance of responses (Wrzesniewski, McCauley, Rozin, & Schwartz, 1997).

The dependent variable in this investigation was the short version of the Mental Adjustment to Cancer Scale (MAC), selected for its specificity in selecting for psychological, rather than physical variables. Originally constructed as a 58-item questionnaire, explanatory factor analysis reduced this psychometrically valid scale to 40-items. It was later reduced further to 33 items representing two higher-order factors reflecting global adjustment: Positive

Mental Adjustment to Cancer and Negative Mental Adjustment to Cancer (Watson & Homewood, 2008). Positive adjustment is a score derived from 15 of 16 original items on a sub-scale designed to measure *Fighting Spirit*, plus two items from a subscale designed to capture *Positive Fatalism*; i.e., “I’ve had a good life; what’s left is a bonus.” The negative adjustment items are comprised of all six items from an original *Helplessness/Hopelessness* subscale, plus five items measuring *Anxious Preoccupation*, four items from the *Fatalistic* subscale and one *Avoidance* item from the original questionnaire. The scale’s authors emphasize the fact that the two scales are “not simply opposites as sometimes assumed ... [but] independent factors which are only marginally correlated and may be different in quality,” (p.15). These authors conducted a factor analysis of the original scale in 1,255 patients, confirming that the new higher order factors (positive adjustment and negative adjustment) highly correlate with the original subscales, with alpha coefficients of 0.81 for each of the two factors, and predict well-being. Replications of the original 5-subscale Mental Adjustment to Cancer have been conducted by researchers in the U.S., Sweden, Australia, France, and Greece (Watson & Homewood, 2008).

Instrumentation

Mental Adjustment to Cancer Scales. Psychological adjustment to cancer was measured by Positive Mental Adjustment to Cancer (PMAC) (17 questions) and Negative Mental Adjustment to Cancer (NMAC) (16

items) scaled by Watson and Homewood (2008). This dichotomous instrument was derived from the validated Mental Adjustment to Cancer (MAC) scale, a 40-item scale containing five dimensions: helplessness/hopelessness; anxious preoccupation; fighting spirit; fatalism (originally called ‘stoic acceptance’); and cognitive avoidance (originally called ‘denial’) in a study by Watson, Greer, Young, Inayat, Burgess, and Robinson (1988). Developed from structured interviews of British cancer patients, the MAC subscales were determined to have acceptable reliability coefficients ($\alpha = 0.65-0.84$), and have been independently validated in Swedish and American cancer patients (Nordin, Berglund, Terje, & Glimelius 1999; Schnoll, Harlow, Brandt, & Stolbach, 1998). In a major adaptation, Watson and Homewood (2008) confirmed that their two higher-order factors, *Positive Mental Adjustment to Cancer* and *Negative Mental Adjustment to Cancer* (PMAC and NMAC, respectively) strongly correlated with the Hospital Anxiety and Depression Scale’s anxiety ($r_s = 0.60$) and depression ($r_s = 0.516$) components. The scales measure unique and independent coping and adjustment attitudes and are thus not combined, but reported separately.

For this analysis, mean PMAC and NMAC scores were calculated, with a cutoff score of 47 or less on PMAC items constituting Low Positive Mental Adjustment to Cancer and a cutoff score of greater than 36 on

NMAC constituting High Negative Mental Adjustment to Cancer, conforming to guidelines by the scale's authors (Watson and Homewood, 2008).

ECOG Performance Status Scale. (ECOG). The impact of cancer on physical function was assessed using a one-item assessment of cancer's impact on activities of daily living, the ECOG Performance Status Scale. This widely-used instrument by Oken et al., (1982) assesses function and quality of life in the context of cancer (Buccheri, et al., 1996). Ability to perform activities of daily living is graded on a scale of 0 to 5, with 0 representing "fully active, able to carry on all pre-disease performance without restriction," 1 representing "restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work," 2 representing "ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours," 3 representing "capable of only limited self-care, confined to bed or chair more than 50% of waking hours, and 4 representing "completely disabled; cannot carry out any self care; totally confined to bed or chair." First published in 1982, the ECOG Performance Status Scale was found by Conill, Verger, and Salamero (1990) to be valid and reliable among physicians (Kendall's correlation

0.75), and between physicians and patients ($\tau = 0.59$). More recently, Buccheri et al. (1996) and Blagden, et al., (2003) validated ECOG performance scores as a highly reliable marker of prognosis after adjustment for sex and stage of disease.

The Work Orientation Scale (ORIENT). This scale is comprised of 10 items drawn from the University of Pennsylvania Work-Life Questionnaire, to assess patients' perspectives on work's role in their lives; e.g., whether they view work as a job, as a career, or as a calling. This scale originally utilized three vignettes and an 18-item set to assess work orientation. As such, it evaluated people's opinions about the position work held in their lives regardless of their working status, present job, future job ambition, job capabilities, or work performance. Further investigation by Wrzeniewski, McCauley, Rozin, and Schwartz (1997) found that 10 true-false items correlated significantly and substantially to the vignette responses (.40 to .55; $p < .05$, two-tailed). These items were therefore used to determine work orientation, categorized as viewing work as a *job*, *career*, or *calling*.

In this analysis, subjects' work orientation was assigned one of these three categories based on the highest of their mean scores on items reflective of work as a *Job*, *Career*, or *Calling*, per the recommendation of the scale's author (Wrzesniewski, personal communication, March 3,

2011).

Work Distress Scale (DISTRESS). This scale consists of original questions constructed by the author based on qualitative studies in which work-related distress was a theme, as well as from personal observation during a series of cancer support groups. An extensive review of the literature was performed to elicit common themes of work-related distress reported by cancer patients in general and targeted focus groups and structured interview sessions. Thirty-seven questions comprised a global distress scale (see Appendix A). Subjects rated each item according to a 6-point Likert scale: *Strongly Disagree* (1 point); *Disagree* (2 points); *Not Sure* (3 points); *Agree* (4 points); *Strongly Agree* (5 points); and *NA*; Does Not Apply (not included in the analysis).

In addition, work-distress items were categorized into three themes aligning with domains of loss conceptualized by Rasmussen and Elverdam (2008), *structural*, *social*, *existential*, plus a fourth theme from the literature related to a lack of *support* specifically related to work themes (SUPPORT). Specific questions included in the STRUCTURAL, SOCIAL, EXISTENTIAL, and SUPPORT variables can be found in Appendix B.

Structural Distress Cluster. This group of 12 items reflects the potential loss of structure, “normalcy,” and security as a result of work

interruption due to cancer.

Social Distress Cluster. This group of 11 items reflects the potential loss of social interaction, group identity, and teamwork as a result of work interruption due to cancer.

Existential Distress Cluster. This group of 8 items reflects the loss of an existential sense of purpose, meaning, individual identity, and pride associated with work interruption due to cancer.

Work-Specific Support Distress Cluster. This group of 8 items reflects a perceived lack of support concerning work-related issues during work interruption due to cancer.

Work Loss (WORKLOSS). This category was derived from participants' endorsement of any direct employment or salary loss pre-diagnosis to post-diagnosis, as indicated by loss of work status (i.e., "full-time" pre-diagnosis to "part-time" or "not working" post-diagnosis) or income.

Work Loss was assigned a score of "1" in the analysis, while no indication of direct employment loss was assigned a score of "0".

Demographic Predictor Data Categories

Age. An ordinal measurement of age was categorized as follows: under 25, 1 point; 26-35, 2 points; 36-45, 3 points; 46-55, 4 points; 56-65, 5

points; 66-75, 6 points; over 75, 7 points.

Sex. A nominal variable, sex was categorized as follows: male (1) or female (2).

Education. This ordinal variable measured the highest educational level obtained, categorized as follows: less than high school, 1; high school, 2; graduated high school, 3; some college, 4; graduated from college, 5; some post-graduate work, 6; post-graduate degree, 7.

Employment Category. This ordinal variable measured type of employment, categorized as follows: labor/manufacturing (1); skilled technical/clerical/service (2); executive/managerial/professional (3).

Income. This variable measured personal and household income in the year prior to cancer diagnosis and in 2009 were categorized as follows: less than \$25,000, 1; \$25,000 to \$50,000, 2; \$50,000 to \$75,000, 3; \$75,000 to \$100,000, 4; more than \$100,000.

Cancer Type. (CACAT) Subjects were asked to write their primary cancer diagnosis. These responses were sorted into common categories; for example, leukemia was listed as a blood cancer. For the analysis, the two most commonly cited cancers, breast cancer and prostate cancer were assigned numbers, as was “Other cancer type.” Breast cancer was designated 1; prostate cancer, 2; and other cancers, 3.

Stage of disease. Subjects wrote their stage of disease, as defined by the

National Cancer Institute. Their responses were sorted and categorized as follows: Stage I, 1; Stage II, 2; Stage III, 3; Stage IV, 4.

Dates of initial diagnosis and recurrence. Subjects reported the year of their initial diagnosis, and, if, applicable, the year a recurrence of their cancer was diagnosed. Recurrence was categorized as present (1) or absent (0).

Work status. Subjects reported work status prior to diagnosis and in 2009. They also reported preferred work status. These responses were categorized as follows: part-time, 1; full-time, 2; student, 3; homemaker, 4; volunteer, 5; retired, 6; and not working, 7.

Consideration of job change. Subjects were asked whether they had considered changing jobs following their cancer diagnosis. These responses were categorized as follows: yes, 1; no, 2. If they responded yes, they were asked to indicate all applicable reasons among the following: for more money/better benefits; for personal satisfaction; to a less stressful job (or retirement); because I could not perform my previous job; and/or because I lost my job. Each of these variables was categorized as being indicated or not indicated by the respondent, as follows: yes, 1; no, 0.

Open-ended responses. Respondents were offered the opportunity to respond to two open-ended questions at the end of the survey. The first eliciting “thoughts and insights into the impact your cancer has had on

your professional life and the role that work plays in your life. The second question offered patients the opportunity to comment on anything else they wished other cancer patients or physicians/nurses/employers/coworkers to know about cancer and work.

Ethical considerations.

Cancer patients are in a position of ethical vulnerability although they are not incarcerated or otherwise fully dependent on an institution or person, since they are reliant on institutions and health care professionals for their medical care, guidance, and support. It was therefore deemed important to ensure that their decision to participate in this research study be carefully considered and freely offered, without any pressure that could be construed to be coming from their physicians or other caregivers. On the other hand, it was noted that cancer patients also may benefit from participating in a research project if they believe their experience and wisdom might help others facing the same challenges in the future. These considerations were paramount in the development of the informed consent form (See Form A, Appendix C) and Questionnaire (See excerpt, Appendix F) that were sent to patients from Antioch University Santa Barbara and a community cancer center in Santa Barbara.

The informed consent statement explained the presumed minimal risks of potential harm that might be associated with completing such a survey, including

emotional discomfort. Recipients were assured that, should such harm occur, they could contact the investigators and resources would be provided for appropriate mental health care. (It should be noted that the community cancer center involved in the study provides no-cost mental health care to cancer patients residing in the area, and this referral resource would have been among those provided to participants who expressed concerns about emotional responses to the questionnaire.)

Only questionnaires returned with a signed Informed Consent Form were included in the study analysis, as patients were informed in a cover letter. For more details on ethical considerations, see Form B, as submitted to the Institutional Review Board of Antioch University Santa Barbara, Appendix D.)

Procedures

The Institutional Review Board of Antioch University Santa Barbara approved the research proposal for this study on Sept. 25, 2010, with minor wording revisions approved on Feb. 16, 2011. It was previously determined that the cancer center involved in the study and its institutional review board would honor the decisions of the Institutional Review Board of Antioch University Santa Barbara.

The questionnaire packets were subsequently sent out to patients. Specifically, the database at a community cancer center was confidentially and

securely accessed by the center's research personnel for the names and addresses of 400 consecutively treated patients at the institution dating backward from a time point dating 3 months prior to the database search. Mailing labels for these patients were placed on stamped questionnaire packets provided by the investigator to the research department at an independent, non-profit comprehensive medical center specializing in the prevention, diagnosis, and treatment of cancer. The research department then mailed the questionnaires, ensuring that the patients' names and addresses remained confidential in accordance with provisions in the Health Insurance Portability and Accountability Act of 1996 (HIPAA), until and unless an individual decided to become a study participant by returning the questionnaire and informed consent to the investigator. Within each packet was a letter of introduction to the study by the research coordinator of the community cancer center; a statement outlining the purpose of the study; an informed consent agreement; contact information for the study author and dissertation committee chair; and a stamped envelope for the return of the survey and the informed consent to Antioch University Santa Barbara.

Participants' responses were coded by number and separated by the investigator from the informed consent forms containing their signatures. These signed informed consent statements, which explained the voluntary nature of participation and confidentiality assurances, were stored in a locked cabinet

separate from the completed questionnaires with patients' responses.

Participants

Subjects were patients who had been treated at a community cancer center for any cancer diagnosis (Stage I-IV) who were at least 18 years old and able to fill out a survey written in English at the equivalent of an 8th grade reading level. Responses to the questionnaire were collected between February 19 and March 25, 2011. Of 400 questionnaires, 84 were returned, for a response rate of 21%. Of these, 5 were returned by family members because the patient had died. Four were returned without a signed Informed Consent, and therefore were not used, leaving a total N of 75. Not every respondent answered every question.

Description of the Study Population

Demographic variables.

Demographic data served as control variables in the analysis. Of those cancer patients who responded to demographic items on the questionnaire, 45 were female (62%) and 28 were male (38%) for a total of 73. The vast majority of respondents were middle-aged to older adults, reflecting increasing incidence of cancer over the lifespan. No individual returned the survey who was under 25 years old. Among adult respondents over 45, age categories were generally evenly distributed: 46-55, 19%; 56-65, 26%, 66-75, 27%, over 75, 22% (See *Appendix E*). Notably, 49% of respondents who reported their ages were over 65, a

traditional age for retirement in the U.S. (although many of these older respondents reported that they were still working at diagnosis and beyond).

The respondents were highly educated (See *Appendix E*). Nearly 58% were college graduates, including 22.5% with post-graduate degrees. Just one respondent reported having less than a high school education, and just 7% reported that their highest level of education was a high school degree.

Work-related variables. A solid majority of respondents reported that their professional and employment category was Executive/Managerial/Professional (74%), as opposed to Skilled Technical/Clerical/Service (20%) or Labor/Manufacturing (6 %). Nearly 62% of 61 respondents who answered income questions fell into a personal income category in the year prior to their diagnosis of \$50,000/year or less, with 38% earning more than that amount. The figures were very similar for 2009 personal income, with 63% earning \$50,000 or less. Mean household income was 3.11 on the 5-point categorical scale, to coincide with the category representing \$50,000-\$75,000/year). More than half (54.7%) of respondents reported a household income higher than \$50,000/year and 28% had a household income of \$100,000 or more in the year prior to their cancer diagnosis. Household income declined slightly during 2009 from the year prior to diagnosis. During 2009, half of respondents had household incomes of \$50,000 or less and half had more than \$50,000. The percentage of respondents reporting a household income above

\$100,000 remained the same, 28%. With regard to work orientation (Wrzesniewski, 1997), subjects were more likely to view their work as a calling (44%), or as a job (38%) than as a career (18%).

A formula representing loss of work (either by income or employment status; i.e., dropping from full-time work to part-time work post-diagnosis) showed that more than 1 in 5 of respondents (15 of 67) experienced work loss. When current work status was compared to preferred work status, 71% of respondents (49 of 69) reported that they were working as preferred, while 20 (29%) were not working as they preferred. This could mean they were working more than they wished; that is, full-time when they preferred to work part-time, or less than they wished; that is, not working or retired when they preferred to be working part-time or full-time.

Nearly a quarter of the sample (13 of 56, or 23%) reported that they considered changing jobs following a cancer diagnosis. Many of these 13 respondents voiced more than one reason for contemplating such a change, with nine considering retirement or a job with “less stress”; seven, a job offering more “personal satisfaction”; four seeking more money; two because they felt they “could not perform” their prior jobs; and two reporting a job loss that required a search for new employment.

Cancer-related variables. Nearly half (36, or 48%) of 75 respondents were treated for breast cancer, either as a primary cancer or a second cancer.

Some patients reported being diagnosed with more than one cancer type. Next in frequency was prostate cancer, diagnosed in 12, or 16% of patients. Five patients reported a lung cancer diagnosis. Four patients reported a diagnosis of colorectal/anal cancer, with the same number reporting head/neck cancer. Blood cancer, (including Chronic Lymphocytic Leukemia, CLL); sarcoma (including angiosarcoma and liposarcoma), or urinary cancer (including kidney cancer and trans cell cancer) were reported as diagnoses by three patients each, while two patients reported skin cancers, including one with melanoma and one with Merkel Cell Cancer, a rare, aggressive form of non-melanoma skin cancer. One patient reported being diagnosed with pancreatic cancer and another patient, thyroid cancer. (See Table 1)

Table 1

Cancer Types Represented in Study Population

Cancer Type	Number of Patients	Percentage of total
Breast	36	48%
Prostate	12	16%
Lung	5	7%
Colorectal/anal	4	5%
Head/neck (incl. oral)	4	5%
Blood (incl. CLL)	3	4%
Sarcoma	3	4%
Urinary (incl. trans cell)	3	4%
Melanoma/Merkel Cell	2	3%
Pancreatic	1	1%
Thyroid	1	1%

Among 44 patients who described their stage of cancer, the majority (18, or 41%) had Stage I disease, generally reflective of limited disease and a better prognosis than patients with Stage II to Stage IV disease (American Joint Committee on Cancer, 2010). The remaining respondents represented higher stages of disease in roughly equal numbers (8 patients, Stage II; 9 patients, Stage III; 9 patients, Stage IV).

Most patients (52 of 68) were diagnosed with cancer in 2009 or 2010, reflecting the time period accessed within a community cancer center's database. Eight patients reported historically distant initial diagnoses (1965-2004) and seven were diagnosed between 2004 and 2008. Recurrence of cancer had occurred in nearly a quarter of patients (18 of 74, 24%). In one patient, recurrences were diagnosed in 1999 and 2009 after an initial diagnosis in 1989. Three patients had recurrences between 2002 and 2008 and the remaining 15 patients recurred between 2009 and 2011.

Patients who responded to the survey were generally in good enough health to function at a level permitting at least light work. In response to a five-item categorization of functional status (the ECOG Performance Status Scale), more than half (40 of 71) said they were "fully active, able to carry on all pre-disease activities without restriction." Another 22 patients said they were "restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature." These patients might be capable of

continuing to work in their pre-cancer employment, depending on the scheduling of their treatments and the requirements of their jobs. Nine patients reported lower levels of physical function precluding work activities. No patient who responded to the survey was physically disabled (incapable of self-care and confined to bed or a chair).

Work-distress related variables.

This exploratory variable consisted of 37 questions (see *Appendix A*) scored to reflect distress regardless of how they were worded in the questionnaire. (For example, the statement, “It doesn’t bother me to miss work during cancer treatment; I would be happy never having to work in full-time job again,” was reverse-scored, since it is a statement that reflects no work-related distress, but a sentiment reflecting the opposite). Mean responses were calculated. The mean score on the 37-item Work Distress Scale was 2.62, with a standard deviation of .756, among 59 subjects.

Dependent variable (Mental Adjustment to Cancer Scale).

Mean MAC scores were calculated and individuals were identified within the study population who met cutoff scores set by Watson and Homewood (2008) for low PMAC (one Standard Deviation from the Mean in the validation population, equated to a sum of 47 or less in response to the 17 PMAC items), or high NMAC (one Standard Deviation above the Mean in the validation population, equated to a sum of 36 or more in response to the 16 NMAC items).

Respondents' mean total score on Positive Mental Adjustment to Cancer (PMAC) was 51.47, with a standard deviation of 9.23, similar to the mean of 54.06 and standard deviation of 6.81 reported by Watson and Homewood (2008) in a study of 1,255 cancer patients. A total of 19 subjects (27%) in the current study were deemed low in PMAC based on the cut-off score of 47 or less, compared to 52 subjects who were not deemed low in PMAC.

The mean total score for Negative Mental Adjustment to Cancer (NMAC) was 28.76, with a standard deviation of 9.11, compared to a mean score in the Watson and Homewood study of 29.37 with a standard deviation of 6.81. A total of 12 respondents (17%) in the current study met criteria for high NMAC, scoring greater than 36.

Table 2 indicates the basic descriptive statistics for the principal dependent variables.

Table 2

*Work Distress Scale and Clusters and
Positive (PMAC) and Negative (NMAC) Mental Adjustment to Cancer*

Variable	N	Mean	SD
Work Distress	59	2.62	.76
Structural Distress	51	3.04	.88
Social Distress	51	2.86	.84
Existential Distress	46	2.97	.98
Work non-support	50	1.98	.80
PMAC (Total)	71	51.47	9.23
PMAC (mean item)	71	3.03	.54
NMAC (Total)	71	28.76	9.11
NMAC (mean item)	71	1.80	.57
PMAC (Watson & Homewood, 2008)	1,156	51.06	6.71
NMAC (Watson & Homewood, 2008)	1,148	29.37	6.81

Preparation of Data

Data were organized to utilize two dependent variables related to mental adjustment to cancer: Positive Mental Adjustment to Cancer (PMAC) and Negative Mental Adjustment to Cancer (NMAC). Demographics, cancer-related variables, and aspects of work-related distress (both as a global scale and by cluster to represent structural, social, existential, and work-related support themes) served as predictor variables. Predictor variables were entered into SPSS Version 19, using numeric coding to distinguish responses.

Statistical Analyses

Linear and logistic regression analyses were conducted using SPSS Version 19 to investigate correlations between predictor variables, including work-related distress, and the dependent variables, psychological adjustment to cancer (PMAC and NMAC). A factor analysis was planned to identify distinct and valid clusters of variables within work-related distress; however, not all participants responded to every distress-related item, providing insufficient data to identify valid clusters within responses. A one-way analysis of variance (ANOVA) was conducted to examine item and scale correlations with PMAC and NMAC. A second ANOVA was conducted to examine item and scaled response differences between positively adjusted and non-positively adjusted subjects, and negatively and non-negatively adjusted subjects.

Results

Positive Mental Adjustment to Cancer

The first hypothesis posited that work distress is negatively associated with Positive Mental Adjustment to Cancer (PMAC) when controlling for potentially confounding variables. Pearson correlations were calculated between the major predictor variables and the positive Mental Adjustment to Cancer scale (PMAC). All correlations were nonsignificant except sex ($r = .24, p < .05, N = 71$) and the three categories of cancer (breast, prostate, or other) (CACAT) ($r = -.33, p < .005, N = 70$). Likewise, a stepwise linear regression analysis found that the only significant predictor of PMAC was CACAT ($R = -.32, p < .002, N = 75$). To further explore the effects of category of cancer, a one-way ANOVA analysis utilizing the three categories of cancer as factors found a significant difference between groups on PMAC ($F = 4.138, df = 2, 67, p = .02$). Posthoc analysis using Scheffe's test found that breast cancer patients had a significantly higher PMAC ($M = 54.48$) than patients in the "other cancer" group ($M = 47.87$), while prostate cancer patients' scores ($M = 50$) did not vary significantly from those of breast cancer patients or patients with other cancers.

When CACAT was eliminated as a potential confounder, mean PMAC scores were higher ($p < .05$) among females ($M = 53.25, SD = 8.11$) than among

males ($M = 48.74$, $SD = 10.29$).

Work Distress as a global variable was not significantly associated with PMAC, nor were clusters of distress. Of interest, other independent variables that might be hypothesized to contribute to PMAC—a low stage of disease, absence of disease recurrence, or full physical capacity – also failed to reach significance in this analysis.

Subjects were then classified according to their PMAC scores as having positive adjustment (a score of 48 or greater) or low positive adjustment as suggested by Watson and Homewood (2008). Nineteen subjects (34%) met the criteria for low positive adjustment while 52 did not. A logistic regression analysis was then performed with the previously described predictor variables to distinguish these two groups: those patients positively adjusted to cancer and those with negative positive adjustment. Categories of cancer (CACAT) again emerged as the only significant variable. Further, the Spearman's rho correlation between CACAT and low PMAC was .30, significant at the 0.05 level (2-tailed).

Negative Mental Adjustment to Cancer.

Results of the study supported the second stated hypothesis; i.e., that work-related distress predicts NMAC when accounting for other possible confounders. The more strongly a cancer patient endorsed a sense of work-related distress, the higher his or her scores were on the Negative Mental Adjustment to

Cancer (NMAC) Scale, when controlling for age, sex, education, cancer type and stage, physical impact of disease, employment category, magnitude of employment loss, and work orientation.

Pearson correlations were calculated for the various predictor variables and NMAC. Several significant correlations were found (see Table 3). A stepwise linear regression analysis (replacing missing data with the population mean) determined that the composite variable “Work Distress” (DISTRESS) was strongly correlated with NMAC, accounting for 24% of the variance, followed by lower job/employment category (15%), lower physical function (measured as ECOG Performance Status) (9%), and not working as preferred (5%), as shown in Table 4. Together, these factors accounted for 53% of the variance of NMAC. Of note, most demographic characteristics, including age, sex, education, cancer type and stage, presence or absence of recurrence, magnitude of employment loss, and work orientation were not correlated with NMAC in the regression analysis. Once again, age, education, income, magnitude of work loss, and cancer stage were not predictive of either Positive or Negative Adjustment to Cancer, and in this analysis, even physical function (ECOG Performance Status) failed to reach significance as a predictor of psychological adjustment to the disease.

Table 3

Pearson's Correlation of Variables, Including Distress and Clusters, and Positive and Negative Adjustment to Cancer

Variable	Measure	Positive Adjustment Average	Negative Adjustment Average
Work Distress	Pearson Correlation N	-.10 59	0.53** 59
Structural Distress	Pearson Correlation N	-.03 51	-.52** 51
Social Distress	Pearson Correlation N	.08 51	.13 51
Existential Distress	Pearson Correlation N	-.24 46	.31* 46
Work Support Distress	Pearson Correlation N	-.01 50	.27 50
Age	Pearson Correlation N	-.16 71	-.19 71
Sex	Pearson Correlation N	.24 71	-.13 71
Education	Pearson Correlation N	.06 69	-.21 69
Employment Category	Pearson Correlation N	-.03 63	-.51* 63
Cancer Type	Pearson Correlation N	-.33** 70	.27* 70
Cancer Stage	Pearson Correlation N	-.12 43	.39* 43
Physical Function	Pearson Correlation N	-.22 69	.46** 69

* $p < .05$, two-tailed

** $p < .01$, two-tailed

Table 4

Significant Predictors of Negative Mental Adjustment to Cancer in Linear Regression Analysis

Variable	R	R ²	R ² change
Work Distress	.45	.24	.24
Employment Category	.63	.39	.15
Physical Health Status	.70	.49	.09
Not Working as Preferred	.73	.53	.05

The system suggested by Watson and Homewood (2008) was used to classify individuals in the current study with Negative Mental Adjustment to Cancer. Because only 12 subjects were classified as having Negative Mental Adjustment (HINEG), a logistic regression was deemed inappropriate.

Multiple *t* tests were conducted comparing the means of the demographic and predictor variables as well as DISTRESS and the four clusters (Structural, Social, and Existential Distress, and a lack of work-specific Support) for the HINEG and Non-High Negative Adjustment to Cancer (NHINEG) groups. Significant differences between means included items relating to physical health function (ECOG Performance Status, Professional/Employment Category, Structural work distress, Global work distress, and age, as shown in Table 5.

Table 5

Compared Means of Selected Variables for Patients Negatively Adjusted to Cancer(NMAC) and Non-Negatively Adjusted Patients

Variable	NMAC	N	Mean	SD	t
Age	No Yes	59 12	5.49 4.75	1.22 1.06	1.95*
Sex	No Yes	59 12	1.61 1.58	0.49 0.51	0.17
Education	No Yes	57 12	5.09 4.33	1.48 1.56	1.59
Employment Category	No Yes	52 11	2.81 2.09	0.44 0.83	4.09**
Cancer Type	No Yes	59 11	1.79 2.26	0.89 1.01	-1.60
Cancer Stage	No Yes	35 8	2.06 2.75	1.21 1.04	-1.49
Physical Health Function	No Yes	58 11	1.47 2.45	0.68 1.04	-4.04**
Not Working as Preferred	No Yes	57 10	3.21 2.50	2.11 2.07	0.99
Work Distress	No Yes	48 11	2.50 3.11	0.75 0.61	-2.51*
Structural Work Distress	No Yes	40 11	2.87 3.69	0.82 0.83	-2.95**
Social Work Distress	No Yes	41 10	2.82 2.98	0.89 0.62	-.540
Existential Work Distress	No Yes	36 10	2.90 3.19	0.98 0.99	-.804
Non-Support Distress	No Yes	40 10	1.89 2.34	0.78 0.84	-1.62

* $p < .05$, two-tailed

** $p < .01$, two-tailed

Contributors to Work Distress

Hypothesis 3 relates to the four domains of work distress (Structural, Social, Existential, and the lack of Work-specific Support) identified in the literature and the author's experience. It had been hoped that analysis of the work distress dimension would yield these four clusters. Unfortunately, the limited number of cases prevented a factor analysis of the 37 items, many of which were not answered by all participants, in the DISTRESS scales.

Instead, since this study is intended to advance understanding of work-related distress, potential relationships were explored among the original identified domains and PMAC and NMAC to identify any foci of future research. To this end, a stepwise linear regression using the four a priori domains of distress (structural, social, existential, support) along with the demographic, cancer-related and work-related variables was conducted to predict PMAC and NMAC. When missing individual data were replaced by the mean in the regression, none of the work distress clusters were correlated with PMAC. However, the *Structural* work-related distress significantly correlated with NMAC ($r = .45, p < .0001$), accounting for 15% of unique variance. As can be seen in Table 6, only Employment Category accounted for a greater proportion of variance (22%), this item reflecting higher NMAC among individuals whose jobs fit into the labor/manufacturing or skilled/technical/clerical/service categories

Table 6

Results of Linear Regression to Predict Negative Mental Adjustment to Cancer Using Work Distress Cluster Variables

Variable	R	R ²	R ² change
Employment Category	.47	.22	.22
Structural Work Distress	.61	.37	.15
Physical Health Function	.68	.46	.09
Pre-diagnosis Household Income	.72	.52	.06
Cancer Stage	.75	.56	.04
Sex (Male versus Female)	.77	.60	.03

compared to the executive/managerial/professional category. Other significant correlates with NMAC were lower physical function (ECOG Performance Status) (9%), lower household income prior to diagnosis (6%), higher cancer stage (4%), and male sex (3%). The total R for these six variables was .77, representing 59% of the variance in NMAC.

The effect size of differences between non-negatively adjusted patients and those who met criteria for NMAC was calculated for each significant variable. The Cohen's d for response differences between negatively adjusted patients and non-negatively adjusted patients concerning *structural* work distress was 1.02, suggesting a large effect size (Table 7). A large effect size was also seen for the global group of work distress items (Cohen's $d = .85$). Very large effect sizes were seen for two demographic variables: employment/professional category and physical health (1.38 and 1.34, respectively), measured using the ECOG Performance Status measure. The relative effect sizes for the distress clusters and the control variables are described in Table 7.

A post-hoc power analysis for the significant variables in Table 7 yielded the following results: Structural work distress: .90 (one-tailed); global work distress: .79 (one-tailed); employment/job category: .98; and ECOG Performance Status, .99 (one-tailed).

An analysis of the relationship of individual work distress items to cancer adjustment was then conducted using Pearson correlations. Two items correlated

Table 7

Means and Effect Sizes: Predictor Variables of Negative Mental Adjustment To Cancer

Variable	n	Mean	SD	Cohen's d	r
Structural Work Distress					
Negatively-adjusted	11	3.69	.83	1.02*	.45
Non-negatively Adjusted	40	2.87	.82		
Global Work Distress					
Negatively-adjusted	11	3.11	.61	.85*	.39
Non-negatively adjusted	48	2.50	.75		
Job/Employment Category					
Negatively-adjusted	11	2.09	.83	1.38**	.57
Non-negatively adjusted	52	2.81	.45		
Physical function (ECOG)					
Negatively-adjusted	11	2.45	1.04	1.34**	.56
Non-negatively adjusted	58	1.47	.68		

($p < .05$) with PMAC :“My work friends have become even closer friends following my cancer diagnosis,”($r = .34, n = 35, p < .05$) and “I have more positive interactions with people at the (community cancer center) than I did at work” ($r = -.35, n = 41, p < .03$). Nine items were found to be significantly correlated with NMAC and are listed in Table 8.

Table 8

Individual Items That Correlated with Negative Mental Adjustment to Cancer

Item	<i>n</i>	<i>r</i>
I don't like to miss work due to my cancer because people my age should be working	35	.38*
My cancer diagnosis seemed to make some of my co-workers pull away from me.	31	.37*
I miss work because working means I'm somebody.	31	.44*
Because of my cancer, I will have to work harder to achieve my career goals.	28	.55**
I have received plenty of information about cancer, sick leave, disability, and my other benefits.	35	-.39*
I still hear from some of my work friends, but I definitely feel out of the loop.	27	.45*
I worry about not being able to work like I once did because of memory, concentration, and/or energy problems.	38	.40*
I worry about not being able to work like I once did because I haven't been able to keep up with the skills and changing challenges of the job world.	35	.41*
I believe that I have been discriminated against by my workplace due to my cancer.	33	.43*
* <i>p</i> < .05, two-tailed		
** <i>p</i> < .01, two-tailed		

While *Work Distress* as a global construct and *Structural* work distress items emerged as meaningful correlates with negative psychological adjustment to cancer, open-ended responses of subjects provided rich detail to the survey results on these and other work-related topics.

Open-ended Survey Responses

Many subjects took the opportunity to express gratitude to caregivers in their families, coworkers and employers, and health professionals for guiding them through the challenging process of cancer diagnosis and treatment. Others offered specific and general comments about cancer and how it influenced, or failed to impact, their work lives. These remarks specifically focused on income and job stability, the influence of employers and coworkers on their adjustment, limitations imposed by their disease, its treatment, and/or side effects, and general philosophy regarding work and cancer.

Income. Cancer triggered profound financial consequences for some survey respondents, requiring major life decisions to be balanced with the rigors of treatment.

A brain cancer patient in the 56-65 age range wrote:

As a single mother of a 22 and 25 year old the diagnosis came as a huge shock to all of us. I had to move from my rented home because income dropped substantially. I had to quit my 28-30 year teaching career. At the time I was in debt.

A breast cancer patient aged 46-55 wrote:

Working full time during my treatment was extremely difficult. I also had no choice that I thought of because I am the sole support for my family and did not want to miss a mortgage payment and lose health insurance.

“Having cancer is overwhelming, but when the *bills* come, it is more overwhelming for many,” wrote a 56-65-year-old patient with anal cancer.

Job stability. Patients wrote of losing their jobs, or fearing the loss of their jobs or insurance benefits.

One breast cancer patient, aged 46 to 55, wrote:

My husband and I own a landscaping business. We have 13 employees. I work part time in the office; my husband was able to fill in for me when I was sick. I think if I had a regular job it would have been much more difficult and I probably would have been fired for missing so much work.

“ I did lose my job and feel that people who are diagnosed with cancer should not lose their jobs unless they cannot return in a year,” wrote a 56-65-year-old breast cancer patient.

A male patient aged 46-55 with prostate cancer wrote, “Radiation in 2010 was scheduled at a *bad time*: the peak of the spring work season. I lost 1-2 months of income and was bitter about it, but I got over it and resumed work within two

weeks of treatment.

Wrote a 35-45-year-old woman with breast cancer:

I feel guilty feeling like cancer ruined my life. I lost my job, (and) physically, mentally, and emotionally will never be the same. I've had to move and I'm broke, but I do have a lot of faith in God for a better future. I was diagnosed 2/2009, but from the biopsy to the end of my treatment in 4/2010 I had one problem after another with hematomas, infection, and toxicity. Then I learned I lost my job and have become depressed.

A breast and thyroid cancer patient in the 26-35-year-old range wrote:

With the economy as it is, my biggest fear is losing my job and thus, my health insurance. On bad days, I go so far as to imagine myself dying of cancer because I was uninsured. Even though I am confident I can find a new job should I lose my current job, I fear that I can still be denied insurance due to my pre-existing condition. I'm unclear what protections I have, if any, as a result of the healthcare reform act.

Another breast cancer survivor, 36-45, wrote:

I owned a small business that I loved and lived for. The economy hit it hard and I had to close it down four months prior to my diagnosis. I was in the process of starting another business and ...

trying to get an individual insurance policy because I was losing my current one due to the business closure. When I was diagnosed, I was not sure if I was insured. That was the hardest part of my treatment: worrying about how to pay for the medical services I needed. It is extremely hard to focus on healing when you are stressing about money.

One 26-35-year-old breast cancer patient wrote:

When I came into the cancer center to check in, the front desk announced loudly (and jokingly) that I was the “infamous one” because my insurance still had not paid for my scan. She was just teasing but it almost brought me to tears due to the financial difficulties that I was having.

Support from coworkers. A number of survey respondents wrote of support they received or did not receive from coworkers.

One breast cancer patient in the 46-55-year-old age group wrote:

When I went through my chemo treatments it made it very difficult to fully monitor the projects I was working on. At times I fell behind and my coworkers had to help me. They were very helpful and never complained about picking up the slack. Don’t be afraid to ask for help. Now I make it a point to help my coworkers

as much as possible to show my appreciation for everything they have done for me. I am very blessed to work with such great and supportive friends within my department,” wrote a breast cancer patient in the 46-55-year-old range.

A breast cancer patient in the 56-65-year-old range agreed. “I’ve been very lucky. My family, my friends, and coworkers have been there for me one hundred percent. I’ve never felt such love and support,” she wrote.

A retired male with aggressive skin cancer noted, “I have told friends and family about the cancer, but not friends from work, mostly because I don’t want the sympathy.”

A self-described farmer and rancher aged 66-75 who “worked every day” during treatment wrote, “Old co-workers and friends have been very supportive.”

Employer support: Some patients described highly accommodating employers, flexible job duties, and a supportive work environment.

“I was a bookkeeper at the time of original diagnosis. My supervisor was very supportive and let me set my own hours,” wrote a breast cancer patient aged 66-75.

Another breast cancer patient, aged 46-55, noted:

I am fortunate to have had a director who had gone through the exact same cancer before me. I was supported by her and coworkers and allowed the ability for treatments. This made the fact of cancer in my life while a big deal, not a derail of my every day routine. I also work part time and feel blessed to have good insurance through my employer.

A 56-65 year old breast cancer patient said she was diagnosed while working with disabled adults:

I loved this work and hope that I am able to return to it. I felt very supported when I first became symptomatic, after diagnosis, and to this day, though I have been unable to work for about a year now. Work provides normalcy. Those that I worked with and for were all exquisitely kind.

Wrote another breast cancer patient, aged 26-35, "I work in a very supportive environment where I was directed to focus on my health. My coworkers filled in the void I left during the months I was in treatment. This was crucial to my success. If only all employers were this supportive."

"My workplace was exceptional in accommodating me. In a strange way, this health setback opened my eyes to LIFE! In spite of everything that happened, I feel lucky to be now healthy and enjoying my life again," wrote a 56-65-year-old male cancer patient.

Employer non-support: Other patients described the opposite reaction from their employers and places of business.

Wrote a 56-65-year-old breast cancer survivor:

The fifth month of treatment, I came down with pneumonia and staph infections in my nose and was hospitalized for two weeks. I was out of work for four months because of weakness and fatigue. Although my boss (male) didn't think I was capable of returning to my job, I've returned and am very happy. Although I do get tired (it's been 3 months) I make sure I get a good night sleep and I'm ready to go again. I never wanted to be a victim, never wanted anyone to feel sorry for me or think I was sick.

“When my daughter was ill (also with cancer) and I needed to be with her, my employer was neither kind nor sympathetic. What a huge difference that would have made,” wrote a breast cancer patient in the over-75 age category.

A male patient aged 56-65 with liposarcoma wrote:

Although my employer is sympathetic, my workload is not adjusted for my decrease in energy. I plan to retire earlier than planned pre-diagnosis, when the demand is too great. I believe more liberal use of disability would inform employers that their employee is not 100%.

Need for support/advice. A number of patients offered the opinion that more information from health care providers or employers about work-related issues may have been helpful to them.

Wrote one woman with breast cancer, aged 46-55:

It would be a good idea to have the physicians suggest (that) the patient talk to their human resource(s) department about options for time off during treatments to best suit the needs of the patient financially. Example: sick time/disability/comp time/work part time and part time disability.

Work/retirement plans. A few patients wrote about their goals concerning the future, whether that meant a return to the workforce or an early retirement.

“I was retired, divorced, and scared. But...that’s behind me. I’d love some sort of job!” wrote a woman over 75, who recovered from sarcoma.

A breast cancer patient, aged 56-65, remarked:

I do believe working during treatment was beneficial. I am retiring at the end of 2011 not because of cancer but to do other things: volunteer work, travel, etc. Planned to do so before cancer, but the diagnosis made me a bit more sure that I had another chapter to live.

“If it is possible to continue working some during cancer treatment, it is a good idea. For me it was a good transition to retirement,” wrote a 66-75-year-old woman with breast cancer.

Work-related limitations. Patients commonly wrote about changes in their ability to work, or conversely, their realization that their work-related abilities were unchanged after treatment.

“It has definitely changed my style of working: less working, no more sport activities or exercise and more gained weight, no more heavy lifting,” said a 56-65-year-old woman with a hematologic cancer.

“The only post-operation effect I can think of is the tiredness that radiation treatment left me with,” wrote a 66-75-year-old artist with prostate cancer. “But this is improving.”

A 46-55-year-man with prostate cancer wrote, “I don’t have any side effects which impact my strongly physical work.”

“My cancer had little impact on my professional life. I am back to work and it’s like I never left. The most challenging thing has been difficulty doing basic math in my head or remembering words. I’ve been told this will improve with time,” wrote a survivor of breast and thyroid cancer, aged 26-35.

Another breast cancer patient, aged 46-55, wrote:

I have problems with my cognitive memory and haven’t been able to keep my job. When I tried to return, I was exhausted and I can’t

remember the easiest things. At times I blank out on a computer program that I have used for ten years. Please acknowledge that there is a genuine problem beyond so-called 'chemo-brain' that makes certain types of working very difficult.

Resiliency. Some survivors emphasized that cancer has had a minor impact on their lives and their work.

An 82-year-old mental health nurse who continues to work part-time wrote, "The cancer was caught early and had no affect on my life."

Cancer was "just a bump in the road," wrote a 66-75-year-old man who is still working, following treatment for prostate cancer.

"I am happy and healthy. I love my work once again. I look forward to each and every day, and I love helping others," wrote a breast cancer patient, aged 26-35.

A woman aged 46-55 with breast cancer wrote, "I never missed any work. My cancer was not a challenge for me. I am a nursing instructor and I had ample support during my treatment."

Philosophical beliefs on work and life during cancer and beyond. Many patients shared thoughts about working during treatment for cancer, and how their life perspectives had changed following diagnosis.

“I think that because I worked and am still working it gave my life purpose and a reason to get up and get going in the morning...even if I didn’t feel like it,” wrote a 56-65-year-old woman with breast cancer.

A patient with prostate cancer who continued to work part-time during treatment for prostate cancer wrote, “Dealing with my clients gave me a sense of purpose.”

“I have enjoyed working but have always placed family first,” wrote a breast cancer patient in the 56-65-year-old age category. “Cancer taught me to care about myself and reduce stress caused by work place issues.”

A male lung cancer patient aged 66-75 wrote:

Work gave me a sense of importance, of being ‘worthy,’ and/or needed. Work allowed me to be with people on a regular, constant basis. Cancer isolates a person, physically and emotionally, from the ‘normal’ world.

“Our new job is health – It is difficult to put health first. There is guilt associated with letting family and work down because of illness,” wrote a breast cancer patient, aged 46-55.

Discussion

This quantitative study sought to further clinical and scientific knowledge about work-related distress in adult cancer patients. It was determined that work-related distress is associated with negative psychological adjustment to cancer in a population of working aged patients at a community cancer center. Specifically, *structural* losses associated with work interruption predicted negative psychological adjustment in this group. Patients' responses to open-ended questions at the conclusion of a Likert-scaled questionnaire further illustrate that work distress is real, multi-faceted and a significant contributor to the way individuals conceptualize their cancer stories.

A questionnaire sent to 400 consecutive patients at a non-profit community cancer center elicited responses to a series of questions derived from the literature and clinical practice concerning work-related distress.

A total of 75 surveys were returned. Patients did not respond to all items of the questionnaire, which included demographic, health, and occupational variables as well as scales previously validated to measure work orientation and psychological adjustment to cancer, both negative and positive. Whether the analysis was confined to fully-complete questionnaires or whether statistical adjustments were made to account for missing data, work distress (as captured in a series of 37 questions) emerged as a significant correlate to NMAC (Negative Mental Adjustment to Cancer).

In a stepwise linear regression analysis, work distress accounted for .24 of the variance in NMAC. Other significant contributors included lower employment status (.15), lower physical function (.9) and not working as preferred (.5), for a combined .53 of the variance in NMAC. This is a powerful finding, even considering the relatively small number of participants, and argues for more research into work distress as a potentially important facet of psychosocial health in cancer patients. The fact that work distress accounted for such a significant proportion of NMAC carries heightened import when considering the other relevant variables, many of which are not amenable to intervention. Patients with lower-level jobs (job/employment status) could be presumed to be dealing with more extreme financial hardship as a result of their disease, as compared to patients with higher-level jobs with better benefits and perhaps more household savings in reserve for emergencies such as a life-threatening illness. It is, as well, not surprising that patients' negative adjustment is impacted by compromised physical function, as reflected by ECOG Performance Status Score). In most cases, worsening disease would account for this lower score. Patients with a lower ECOG score may be suffering pain and/or other sequelae of their cancer and by definition are not fully mobile and able to attend to their daily functions. The final, albeit minor, contributor to NMAC was "not working as preferred," determined by post-diagnosis job status and preferred job status (i.e., currently working part-time or not at all, when full-time work was preferred by the patient).

It makes sense that such individuals would be more negatively adjusted to cancer, since they are reporting in a very clear manner that the disease's toll has included an unwelcome shift in their work status. Although this variable is not part of the distress scale, it provides yet another example that work is a significant part of cancer patients' lives, and that when it is interrupted or altered, their psychological adjustment suffers.

When negatively adjusted patients and non-negatively adjusted patients were compared, the Cohen's *d* effect size difference between these two groups was most significant when comparing responses to questions about the *structural* work-related distress (1.02), work-distress in general (.85), employment category (1.38) and physical function (1.34). A post-hoc power analysis revealed that the sample sizes for these variables were adequate in all cases except global work distress (.79, one-tailed). Since the power calculation determined that the sample size was sufficient for predicting NMAC based on *structural* work distress, it can be assumed that within this cluster lies the core driver of work-related distress.

Positive Mental Adjustment to Cancer (PMAC) was not associated with work distress in this study. Indeed, the only significant correlations with PMAC in a Pearson's analysis were sex ($r = .24$) and category of cancer ($r = -.33$), reflecting a strong association between females with breast cancer and PMAC that was not seen among members of both sexes with other forms of cancer. This finding was borne out in other statistical analyses conducted for the study,

including a stepwise linear regression analysis that found only cancer category (i.e., breast cancer versus other forms of cancer) to be a significant predictor of PMAC.

Although it was not the focus of the study, the results suggested that breast cancer patients may have a higher positive mental adjustment to cancer than prostate cancer patients or those with other types of cancers. The sample size in this study was too small to draw conclusions about this finding. However, future researchers might well pursue this intriguing issue.

This study arose from a clinical practice setting, where patients attending community support groups shared poignant stories about the impact cancer had on their work lives. The emotional power of those stories echoes in the remarks of patients who were able to recount details of their personal experiences at the end of the survey. They describe profound gratitude to empathetic employers and express disappointment toward those who doubted their ability to continue as productive employees, or worse – laid them off before they could try. Their remarks — as well as the study’s statistical findings — closely track with sentiments outlined in the literature from purely qualitative studies regarding work as a source of structure, social connectedness, meaning and purpose for patients struggling with cancer.

These conclusions should not be surprising, despite the fact that they have received little attention in oncologic and psychological literature. In Western

culture, work is highly prized and considered integral to a balanced, fruitful, and esteemed life. When work is interrupted by disease or circumstance, it follows that people suffer emotional as well as financial consequences. In holistic and culturally sensitive practice, clinicians should be attuned to such distress, just as they elicit and address family-related concerns.

The significant findings in the study focusing on *structural* roles of work are worth considering in future research and in clinical practice. While it would be difficult to construct ways to systematically ease the existential pain of individuals who feel that cancer has deprived them of their identity or meaning in their lives, it is less daunting to imagine ways that employers, health professionals, and mental health professionals might address cancer patients' yearning for simple structure in their days. They looked to work as a reason to get up in the morning and a means of establishing a routine. Without it, they are bored and they feel out of sync with what they consider to be "normal" life for adults. The generativity, security, and structural developmental functions of work in adult life lend individuals a sense of control over their lives.

Other important elements within *structural* work distress as defined in this study are financial security and physical and mental work-related abilities. Cancer patients expressed a sense of troubling vulnerability in these areas, both through their answers to quantitative items and the open-ended section of the questionnaire. Increasing attention to quality of life as it relates to cancer patients

must not fail to appreciate the specific psychological toll exerted by uncertainty about employment stability, health care insurance, and housing. Additionally, side effects of treatment as well as the disease itself compromise individuals' confidence that they will be able to return to the careers they interrupted with energy, aptitude, physical function, and a sense that they are up-to-date with the requirements, knowledge base and tasks they will need to perform. Addressing these fears and the realities behind them will require effort on the part of employers as well as medical and mental health professionals, so that survivors may look forward with optimistic anticipation to a productive and secure return to the workplace, and those who cannot return to working life may focus on their families and legacies in a way that is honoring, developmentally attuned, and emotionally resonant to their new phase of life.

Study limitations

Because this study involves a survey rather than a validated scale, the objective was to determine whether work-related distress is independently associated with adjustment to cancer, after controlling for important variables. The findings are exploratory, rather than conclusive, pointing the way to future priorities in studies aimed at assessing the dimensions, and magnitude of work-related distress.

A sample size of 400 patients was selected not as a result of a power analysis (required for validated scales but not surveys) but because it was hoped

that enough cancer patients would respond to provide a variety of viewpoints in this preliminary attempt to assess work-related distress in a quantitative fashion. A total of 84 surveys were returned, for an overall response rate of 21%. However, 5 surveys were returned by family members, with notes indicating that the patient to whom the envelope was addressed had died. Four surveys were unusable because the return envelopes did not contain a signed informed consent form. The usable response rate, therefore, was 75 of 400 (roughly 19%).

The patient population targeted by the survey is representative only of individuals being treated for cancer at one community outpatient medical center, the majority of whom have private insurance coverage, Medicare, MediCal, or a combination of these financial resources. Santa Barbara County is not a major population center (estimated 2009 population, 407,057, U.S. Census) nor home to any major academic medical center (although Los Angeles, approximately 100 miles to the southeast, offers patients who are willing to travel many choices for tertiary cancer care at university centers, including the University of California Los Angeles Jonsson Comprehensive Cancer Center and the University of Southern California Norris Comprehensive Cancer Center.) Santa Barbara's population is not representative of the U.S. population, being 89% white, compared to 80% nationally, with 40% persons of Hispanic or Latino origin, compared to 16% nationally. Black persons are notably underrepresented in the Santa Barbara County population at 2.4%, compared to 13% nationally.

Respondents were not asked to state race or ethnicity in this study. The mean 2009 household income of respondents was approximately \$50,000, roughly comparable to the U.S. household income in 2008, \$52,029, but less than the average household income in Santa Barbara County for 2008, \$60,645 (U.S. Census).

Findings of the study therefore cannot be generalized to other community populations, nor to cancer patients treated at tertiary institutions. Furthermore, the findings may not be representative of responses that might be obtained from patients who are too busy, ill, or fatigued to fill out a lengthy questionnaire, or by people who cannot read or write in English and do not have access to a translator who can help them record their responses. One patient did contact Antioch University to express interest in filling out the survey despite limited English proficiency. A fluent faculty member agreed to help him complete the study.

It is notable that the questionnaire was sent to patients in February 2011, in the midst of the aftermath of a deep national recession that officially began in late 2007 and ended in 2009 (National Bureau of Economic Research, 2010). During February, unemployment stood at 8.9% nationally and 12.2% in California, ranked second in the nation in joblessness, behind Nevada. (Bureau of Labor Statistics, 2011). This external source of economic hardship may have influenced study results. Job-related distress may have reflected (or been exacerbated by) economic times, rather than cancer alone. Indeed, several

respondents remarked on the economy in comments at the conclusion of the questionnaire. “With the economy as it is,” wrote a breast cancer patient in the 26-35 age category, “my biggest fear is losing my job, and thus, my health insurance.” Another breast cancer patient in the same age category wrote that she had owned a small business until four months prior to her diagnosis. “The economy hit it hard and I had to close it down...” Uncertain of whether her attempts to obtain individual health insurance had been successful, this patient recounted her worry over “huge financial issues.” “It is extremely hard to focus on healing when you are stressing about money,” she wrote. Had the economy not been at such a critical juncture at the time surrounding this patient’s diagnosis, and others’, it is possible that responses to the questionnaire would have reflected lower levels of work-related distress. In this sense, results of the study cannot be generalized to other economic times, but rather represent a snapshot of work-related distress during a time of national financial hardship.

It is noteworthy that 59% of patients who responded to the survey did not know their stage of cancer. Therefore, the presumption that the conclusions represented a population of mostly early-stage patients who could be presumed to be capable of returning to work, may be erroneous.

Additionally, the study population included few young adults (none under 25 and just four patients under the age of 46) and a significant number of individuals (16) who were well beyond traditional retirement age in the U.S. at

the time of the survey. Since neither age nor work status (full-time, part-time, retired, etc.) was a significant contributor to differences in work distress and psychological adjustment to cancer, it may be that work interruption is equally distressing to some adults whether precipitated by a layoff, retirement, or diagnosis and treatment of a life-threatening illness.

Implications and Recommendations

While more research is needed to build on these results, it seems clear that work-related distress should be considered and addressed by clinicians, employers, and friends and family members of cancer patients. As theorized by Freud and Erikson, work is an important component of most peoples' lives during early and middle adulthood, and increasingly lends meaning and security to late adulthood as well.

Cancer patients would benefit from receiving clear and accurate information and advice about work-related issues such as sick leave, disability, medical and mental health benefits, and return-to-work issues not only from brochures and human relations specialists at their companies, but from their medical and mental health professionals as well. Because of the connection between the loss of *structural* functions of work and negative adjustment, the findings may have implications for individual decision-making about whether

cancer patients continue to work, at least part-time, during treatment, if this is feasible. Just dressing for work, reporting to a job, and reviewing mail and messages, may provide for some patients the sense of “normalcy” they miss when they are in treatment. They may not have to work full-time to derive psychosocial comfort from their work-related routine. Mental health professionals working directly with cancer patients may want to consider asking directly about work-related distress in their patients, rather than dealing with such issues only when they arise in the course of medical treatment, individual or family therapy, or group support.

It is noteworthy that study participants were most negatively impacted by *Structural* issues inherent in work interruptions due to their cancer. The survey items addressing this component of work speak to the most basic life functions offered by employment: financial security, “a reason to get up in the morning,” the daily structure of a routine, a sense of “normality,” a purposeful distraction from boredom and anxiety, and the reassuring sense that one is in sync with the developmental “tasks” appropriate to one’s life stage. Clinicians and employers may want to think creatively about how to replicate these missing elements in the lives of cancer patients during work interruptions. Face-to-face and online support groups might be scheduled during “business hours,” to begin at 9 a.m., for example. Boredom might be addressed by offering cancer patients engaging mental activities during long waits for appointments or arduous days spent

receiving chemotherapy infusions. Certainly, psychoeducation efforts could illuminate the importance of routine and daily structure in the life of a cancer patient. This may be achieved by cultivating the perspective, “It helps me to think of cancer as my new job,” an element of the structural work distress domain that distinguished negatively adjusted patients from those who were coping better with the diagnosis.

Future research

The fact that this broadly-based exploratory study found a significant relationship between work-related distress and negative psychological adjustment to cancer strongly argues for further research into the impact of work interruptions on quality of life in cancer patients. It would be helpful to assess the connection between work-related distress and psychological adjustment to cancer in a larger, more diverse group of cancer patients. From there, a logical next step would be development of a valid and reliable scale measuring work-related distress, with special attention focused on structural distress and loss. If individuals can be identified who are susceptible to, or suffering, work-related distress during cancer treatment, experimental research into preventive and/or therapeutic interventions should be pursued. Moreover, longitudinal research into the development of work-related distress and its natural course would illuminate understanding of whether this is a temporary state among cancer patients that resolves upon return to work in cancer survivors.

References

- Amir, Z., Neary, D., & Luker, K. (2008). Cancer survivors' views of work 3 years post diagnosis: A UK perspective. *European Journal of Oncology Nursing* 12, 190-197. doi:10.1016/j.ejon.2008.01.006
- American Joint Committee on Cancer, "What is cancer staging?" Retrieved from <http://www.cancerstaging.org/mission/whatis.html>
- Andrews, G., & Slade, T. (2001). Interpreting scores on the Kessler Psychological Distress Scale (K10). *Australian and New Zealand Journal of Public Health*, 25(6), 494-497. doi:10.1111/j.1467-842X.2001.tb00310.x
- Blagden, S.P., Charman, S. C., Sharples, L. D., Magee, L. R. A., & Gilligan, D. (2003). Performance status score: Do patients and their oncologists agree? *British Journal of Cancer*, 89, 1022-1027. doi:10.1038/sj.bjc.6601231
- Blustein, D. L. (2008). The role of work in psychological health and well-being: A conceptual, historical, and public policy perspective. *American Psychologist*, 63(4), 228-240. doi: 10.1037/0022-0167.49.3.311
- Brazier, J. E., Harper, R., Jones, N. M., O'Cathain, A., Thomas, K. J., Usherwood, T., & Westlake, L. (1992). Validating the SF-36 health survey questionnaire: New outcome measure for primary care. *British Journal of Medicine*, 305(6846), 160-164. doi: 10.1136/bmj.305.6854.646
- Buccheri, G., Ferrigno, D., & Tamburini, M. (1996). Karnofsky and ECOG

- performance status scoring in lung cancer: A prospective, longitudinal study of 536 patients from a single institution. *European Journal of Cancer*, 32A(7), 1135-41. doi:10.1016/0169-5002(94)94103-3
- Bultz, B. D., & Holland, J. C. (2005). Emotional distress in patients with cancer: The sixth vital sign in cancer care. *Journal of Clinical Oncology*, 23, 6440-6441. doi: 10.1200/JCO.2005.02.3259
- Bultz, B. D., & Holland, J. C. (2006). Emotional distress in patients with cancer: The sixth vital sign. *Community Oncology*, 3, 311-314.
- Bunderson, J. S., & Thompson, J. A. (in press). The call of the wild: Zookeepers, callings, and the dual edges of deeply meaningful work. *Administrative Science Quarterly*.
- Bureau of Labor Statistics, U.S. Department of Labor. "Regional and State Employment and Unemployment – February 2011." Retrieved from <http://www.bls.gov/news.release/pdf/laus.pdf>
- Casso, D., Buist, D. S. M., & Taplin, S. (2004). Quality of life of 5-10 year breast cancer survivors diagnosed between age 40 and 49. *Health and Quality of Life Outcomes*, 2. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC437638>. doi:10-11186/1477-75225-2-25
- Centers for Disease Control and Prevention (2004). Cancer survivorship – United States, 1971-2001. *MMWR*, 53, 526-529. Retrieved from

<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5324a3.htm>

Centers for Disease Control and Prevention (2005). Centers for Disease Control and Prevention Health-Related Quality of Life 14-Item Measure.

Retrieved from http://www.cdc.gov/hrqol/hrqol14_measure.htm

Cleeland, C. S., Mendoza, T. R., Wang, X. S., Chou, C., Harle, M. T., Morrissey, M., & Engstrom, M. C. (2000). Assessing symptom distress in cancer patients: The M. D. Anderson Symptom Inventory. *Cancer*, 89(7), 1634-46. doi:10.1002/1097-0142(20001001)89:7<1634::AID-CNCR29>3.0.CO;2-V

Conill, C., Verger, E., & Salamero, M. (1990). Performance status assessment in cancer patients. *Cancer*, 65(8), 1864-6. doi:10.1002/1097-0142(19900415)65:8<1864::AID-CNCR2820650832>3.0.CO;2-U

Costanzo, E. S., Ryff, C. D., & Singer, B. H. (2009). Psychosocial adjustment among cancer survivors: Findings from a national survey of health and well-being. *Health Psychology*, 28(2), 147-156. doi:10.1037/a0013221

Coyle, N. (2006). The hard work of living in the face of death. *Journal of Pain and Symptom Management*, 32(3), 266-274. doi:10.1016/j.jpainsymman.2006.04.003

Erikson, E. H. (1963). *Eight ages of man*. (2nd ed.). New York, NY: W. W. Norton and Co.

Erikson, E. H. (1980). *Identity and the life cycle*. New York, N Y: W. W. Norton

and Co.

Erikson, E. H. (1982). *The life cycle completed*. New York, NY: W. W. Norton and Co.

Filipp, S. (1992). Could it be worse? The diagnosis of cancer as a prototype of traumatic life events. In L. Montada, S. Philipp, & M. J. Leaner (Eds.), *Life crises and experiences of loss in adulthood* (pp. 23-52). Hillsdale, NJ: Lawrence Erlbaum Associates, Inc.

Foley, K. L., Farmer, D. F., Petronis, V. M., Smith, R. G., McGraw, S., Smith, K., . . . Avis, N. (2006). A qualitative exploration of the cancer experience among long-term survivors: Comparisons by cancer type, ethnicity, gender, and age. *Psycho-oncology*, 15, 248-258. doi: 10.1002/pon.942

Fouad, N. A., & Bynner, J. (2008). Work transitions. *American Psychologist*, 63(4), 241-251. doi: 10.1037/0003-066X.63.4.241

Fryers, T. (2006). Work, identity and health. *Clinical Practice and Epidemiology in Mental Health*, 2, 12. Published online. doi:10.1186/1745-0179-2-12

Hoffman, B. (2007). Cancer survivors at work: A generation of progress. *CA: A Cancer Journal for Clinicians*, 55, 271-280. doi:10.3322/canjclin.55.5.271

Holland, J. C., & Bultz, B. D. (2007). The NCCN guidelines for disease management: A case for making distress the sixth vital sign. *Journal of the National Comprehensive Cancer Network*, 5, 3-7.

Institute of Medicine of the National Academies National Cancer Policy Board

(November 2005). Hewitt, M., Greenfield, S., & Stovall, E., (Eds.), *From cancer patient to cancer survivor: Lost in Translation*. Washington D.C.: Institute of Medicine. Retrieved from
http://www.nap.edu/catalog.php?record_id=11468#toc

Jacobsen, P. B., Donovan, K. A., Trask, P. C., Fleishman, S. B., Zabora, J., Baker, F., & Holland, J. C. (2005). Screening for psychological distress in ambulatory cancer patients. *Cancer*, 103(7), 1494-1502.
 doi:10.1002/cncr.20940

Kennedy, F., Haslam, C., Munir, F., & Pryce, J. (2006). Returning to work following cancer: A qualitative exploratory study into the experience of returning to work following cancer. *European Journal of Cancer Care*, 16, 17-25. doi:10.1111/j.1365-2354.2007.00729.x

Kirkova, J., Davis, M. P., Walsh, D., Tiernan, E., O'Leary, N., LeGrand, . . . Russell, K. M. (2006). Cancer symptom assessment instruments: A systematic review. *Journal of Clinical Oncology*, 24(9), 1459-1473. doi: 10.1200/JCO.2005.02.8332

Kirkova, J., & Walsh, D. (2007). Cancer symptom clusters—a dynamic construct. *Supportive Care in Cancer*, 15(9), 1011 - 1013. doi:10.1007/s00520-007-0259-2

Liu, H. (2008). Changes of satisfaction with appearance and working status for head and neck tumour patients. *Journal of Clinical Nursing*, 17(14), 1930-

1938. doi:10.1111/j.1365-2702.2008.02291.x

Mahar, K. K., BrintzenhofeSzoc, K., & Shields, J. (2008). The impact of changes in employment status on psychosocial well-being: A study of breast cancer survivors. *Journal of Psychosocial Oncology*, 26(3), 1-17. doi:

10.1080/07347330802115400

Main, D. S., Nowels, C. T., Cavender, T. A., Etschmaier, M., & Steiner, J. F.

(2005). A qualitative study of work and work return in cancer survivors.

Psycho-oncology, 14(11), 992 - 1004. doi: 10.1002/pon.913

Mor, V., Allen, S., & Malin, M. (1994). The psychosocial impact of cancer on

older versus younger cancer patients and their families. *Cancer*, 74(S7),

2118-2127. doi: 10.1002/1097-0142(19941001)74:7+<2118::AID-

CNCR2820741720>3.0.CO;2-N

National Bureau of Economic Research. Retrieved from

<http://www.nber.org/cycles/sept2010.html>

NCI National SEER Program Data, 1994-1998. U.S. National Institutes of Health,

National Institute on Aging. *Cancer incidence rate by age group, all sites*

combined, both sexes (rate per 100,000 population). Retrieved from

<http://www.nia.nih.gov/ResearchInformation/ConferencesAndMeetings/WorkshopReport/Figure1.htm>

Neugarten, B. L. (1979). Time, age, and the life cycle. *American Journal of*

Psychiatry, 136, 887- 894. doi:10.1037/0003-066X.49.7.553

- Nordin, K., Berglund, G., Terje, I., & Glimelius, B. (1999). The mental adjustment to cancer scale—a psychometric analysis and the concept of coping. *Psycho-oncology*, 8(3), 250 - 259. doi:10.1002/(SICI)1099-1611(199905/06)8:3<250::AID-PON379>3.3.CO;2-A
- Oken, M. M., Creech, R. H., Tormey, D. C., Horton, J., Davis, T. E., McFadden, E. T., & Carone, P. P. (1982). Toxicity and response criteria of the Eastern Cooperative Oncology Group. *American Journal of Clinical Oncology*, 5, 649-655. doi:10.1097/00000421-198212000-00014
- Parsons, J. A., Eakin, J. M., Bell, R. S., Franche, R., & Davis, A. M. (2008). “So, are you back to work yet?” Re-conceptualizing ‘work’ and ‘return to work’ in the context of primary bone cancer. *Social Science & Medicine*, 67, 1826-1936. doi:10.1016/j.socscimed.2008.09.011
- Passik, . S.D., Inman, A., Kirsch, K., Theobald, D., & Dickerson, P. (2003). Initial validation of a scale to measure purposelessness, understimulation, and boredom in cancer patients: Toward a redefinition of depression in advanced disease. *Palliative and Supportive Care*, 1, 41-50. doi:10.1017/S1478951503030062
- Peteet, J. R. (2000). Cancer and the meaning of work. *General Hospital Psychiatry*, 22(3), 200-205. doi:10.1016/S0163-834(00)00076-1
- Peterson, N. & Gonzales, R. C. (2005). *The role of work in people's lives: Applied career counseling and vocational psychology* (2nd ed.). Florence, KY:

Brooks Cole Cengage Learning.

- Rasmussen, D. M., & Elverdam, B. (2008). The meaning of work and working life after cancer: An interview study. *Psycho-oncology*, 17(12), 1232 – 1238. doi:10.1002/pon.1354
- Schnoll, R. A., Harlow, L. L., Brandt, U., & Stolbach, L. L. (1998). Using two factor structures of the Mental Adjustment to Cancer (MAC) scale for assessing adaptation to breast cancer. *Psycho-oncology*, 7(5), 424 - 435. doi:10.1002/(SICI)1099-1611(1998090)7:5<424::AID-PON322>3.0.CO;2-2
- Short, P. F., Vasey, J. J., & Tunceli, K. (2005). Employment pathways in a large cohort of adult cancer survivors. *Cancer*, 103(6), 1292-1301. doi:10.1002/cncr.20912
- Steiner, J. F., Cavender, T. A., Main, D. S., & Bradley, C. J. (2004). Assessing the impact of cancer on work outcomes. *Cancer*, 101(8), 1703-1711. doi: 10.1002/cncr.20564
- Steiner, J. F., Cavender, T. A., Nowels, C. T., Beaty, B. L., Bradley, C. J., Fairclough, D. L., et al. (2008). The impact of physical and psychosocial factors on work characteristics after cancer. *Psycho-oncology*, 17(2), 138 – 147. doi:10.1002/pon.1204
- Steiner, J. F., Nowels, C. T., & Main, D. S. (2010). Returning to work after cancer: Quantitative studies and prototypical narratives. *Psycho-oncology*,

19(2), 115-124. doi:10.1002/pon.1591

Tournier, P. (1972). *Learn to Grow Old*. London: SCM Press Ltd.

United States Census. (2010). *Santa Barbara County quick facts*. Retrieved from
<http://quickfacts.census.gov/qfd/states/06/06083.html>

Voltaire, F., Cuffe, T. (translator), & Wood, M. (introduction) (2009, reprinted).
Candide: Or optimism. London: Penguin Books Ltd.

Watson, M., Greer, S., Rowden, L., Gorman, C., Robertson, B., Bliss, J. M., &
 Tunmore, R. (1991). Relationships between emotional control, adjustment
 to cancer and depression and anxiety in breast cancer patients.
*Psychological Medicine: A Journal of Research in Psychiatry and the
 Allied Sciences*, 21(1), 51-57. doi: 10.1017/S0033291700014641

Watson, M., Greer, S., Young, J., Inayat, Q., Burgess, C., & Robertson, C. (1988).
 Development of a questionnaire measure of adjustment to cancer: The
 MAC scale. *Psychological Medicine*, 18, 203-209. doi: 10.1016/0022-
 3999(83)90052-1

Watson, M. & Homewood, J. (2008). Mental adjustment to cancer scale:
 Psychometric properties in a large cancer cohort. *Psycho-oncology*, 17,
 1146-1151. doi:10.1002/pon.1345

Watson, M.. & Homewood, J. (2008). Mental Adjustment to Cancer Scale User's
 Manual.

Weber, M., (1904). Die protestantische ethik und der geist des kapitalismus.

Translated by Talcott Parsons (1930) in Routledge Classics (2001). *The Protestant ethic and the spirit of Capitalism*. New York: Allen & Unwin.

Wrzesniewski, A., McCauley, C., Rozin, P., & Schwartz, B. (1997). Jobs, careers, and callings: People's relations to their work. *Journal of Research in Personality*, 31, 21-33. doi:10.1006/jrpe.1997.2162

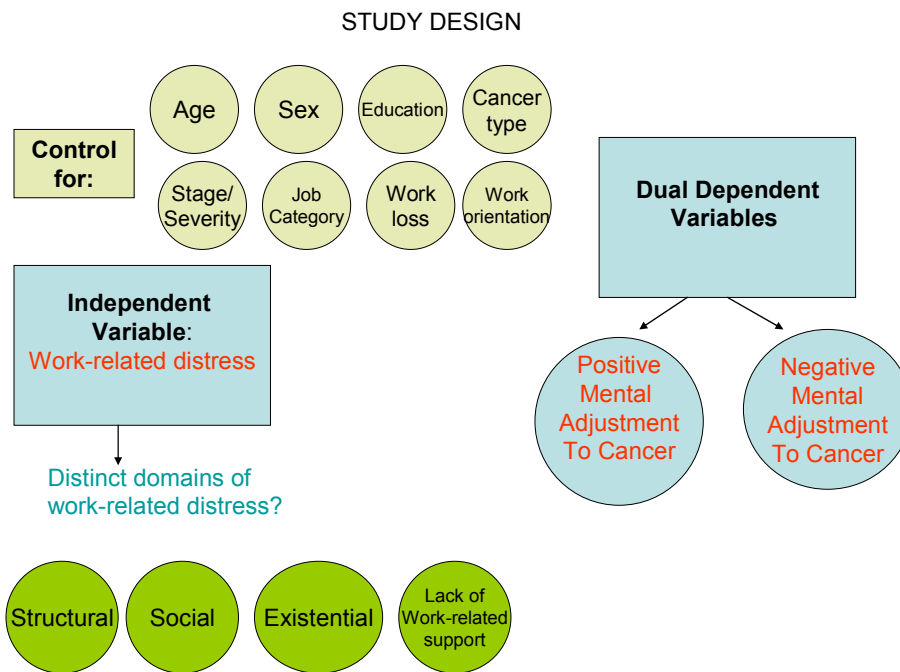


Figure 1. Description of study design, including control variables, the independent variable of work-related distress, and dual dependent variables based on the Mental Adjustment to Cancer Scale by M. Watson and J. Homewood, 2008.

Structural Work Loss Themes Described by Cancer Patients

Theme from the Literature	Citations (Dates)	Symbolic loss	Survey Item(s)
Work represents normality, a “natural” aspect of life at a certain age, structure	Amir (2008) Coyle (2006) Filipp, (2002) Fryers (2006) Kennedy (2006) Main (2005) Neugarten (1968) Parsons (2008) Rasmussen (2008)	“Normality”	“I regret when I have to miss work, because work gives me a reason to get up in the morning and structures my day.” “When I am able to work, it makes me feel normal.” “It doesn’t bother me to miss work during cancer treatment I would be happy never having to work in a full-time job again.” “I don’t like to miss work due to my cancer because people my age should be working.”
Work represents distraction, a relief from boredom, monotony	Amir (2006) Freyers (2006) Kennedy (2006) Main (2005) Steiner (2008)	“Engagement”	“I wish I could work more to keep my mind off cancer.” “I miss working because the life of a cancer patient is boring.” “It helps me to think of cancer as my new job.”
Source of financial stability	Amir (2008) Coyle (2006) Foley (2006) Main (2005)	“Security”	“If I can’t return to work, I’ll really worry about my ability to pay bills and obtain health insurance.”
Sign of recovery, hope; return to health (Conversely: defeat, hopelessness)	Blustein (2008) Main (2005) Parsons (2008) Rasmussen (2008)	“Health”	“To me, working symbolizes recovery and hope.” “If I can’t work anymore, it means the cancer has defeated me.” “I worry about not being able to work like I once did because I haven’t been able to keep up with the skills

			and changing challenges of the job world.” “I worry about not being able to work like I once did because of memory, concentration, and/or energy problems.”
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Figure 2: Distress themes cited by patients reflecting a loss of the structure and stability that work normally provides: literature references, symbolic loss categories, and resulting survey item(s).

Social Work Loss Themes Described by Cancer Patients

Theme from the Literature	Citations (Dates)	Symbolic loss	Survey Item(s)
Work represents friendship, social connection, companionship	Amir (2008) Blustein (2008) Costanzo (2009) Foley (2006) Fryers (2006) Main (2005) Rasmussen (2008) Parsons (2008)	"Connection"	<p>"I hope I can continue to work, mostly because of the camaraderie I have at work."</p> <p>"There are people at work who I haven't told that I have cancer."</p> <p>"I've been disappointed by how some of my co-workers have reacted to my cancer."</p> <p>"I don't miss my coworkers much when I cannot work; my closest friends aren't associated with my job."</p> <p>"When I can't work, I miss knowing what's going on in my coworkers' lives."</p> <p>"My cancer diagnosis seemed to make some of my coworkers pull away from me."</p> <p>"I worry that my coworkers have to work harder because of my cancer-related absences."</p> <p>"I have felt lonely being away from work due to my illness."</p> <p>"I have more positive interactions with people at the Cancer Center than I ever did at work."</p> <p>"I'm relieved to be away from the snobby 'in-crowd' at work when I'm in treatment."</p> <p>"I still hear from some of my work friends, but I definitely feel out of the loop."</p> <p>"My work friends have become even closer friends since my diagnosis."</p>

Figure 3: Social-related distress expressed by cancer patients from the literature and author's clinical experience, along with resulting survey items.

Existential Work Loss Themes Described by Cancer Patients

Theme from the Literature	Citations (Dates)	Symbolic loss	Survey Item(s)
Work represents power; privilege; legitimacy; status (Illness = powerlessness)	Coyle (2006) Fryers (2006)	"Power"	"I miss work because working means I'm somebody." "Being off work during cancer treatment makes me feel powerless."
Source of identity, self-worth; self-esteem	Amir (2008) Fryers (2006) Fouad (2008) Main (2005) Parsons (2008) (Steiner (2008)	"Identity"	"During treatment, I miss work because it is an important source of pride and satisfaction for me." "When I'm in treatment, I miss making important contributions at my workplace."
Source of legacy (philosophical, financial)	Coyle	"Legacy"	"I don't worry about missing work. After I'm gone, people will remember me most for things that have nothing to do with my work."
Purpose, challenge, accomplishment	Blustein (2008) Coyle (2006) Main (2005) Parsons (2008)	"Purpose"	"I hope I can continue to work, mostly because work gives me a sense of purpose." "Because of my cancer, I will have to work harder to achieve my career goals." "I feel like I've wasted much of my life working."
Life's meaning/existence	Coyle (2006) Main (2005) Foley (2006) Fryers (2006)	"Meaning"	"I miss working during cancer treatment because work gives meaning to my life." "The richest parts of my life have nothing to do with work."
Rethinking role of work; restructuring	Amir (2008) Costanzo	"Evolution"	"In a way, cancer was a blessing because it made me realize I was putting

priorities	(2009) Coyle (2006) Foley (2006) Fryers (2006) Main (2005) Parsons (2008) ^w Steiner (2008) Rasmussen (2008)		too much of my time and energy into work.” “Working too hard contributed to why I have cancer.” “I think of fighting cancer as my new “job.” Cancer made me consider changing jobs: *For personal satisfaction
“That’s life;” no regrets	Foley (2006)	“Acceptance”	“Cancer interrupted my work plans, but I have no regrets about that.”

Figure 4. Existential work distress expressed by cancer patients, including literature references, symbolic losses, and resulting survey items.

Work-Related Support, or Lack of Support, as Described by Cancer Patients

Themes from Literature	Citations	Expressed Need	Questions
Desire for work-related guidance, support from physicians, health care professionals	Amir (2008) Frank (2004) Fryers (2006) Kennedy (2006) Main (2005) Parsons (2008) Steiner (2008)	Guidance, direction	<p>"I have received plenty of information about cancer, sick leave, disability, and my other benefits."</p> <p>"My doctor(s) and other health professionals were helpful in advising me about whether I should cut back on work, quit work, or go back to work."</p> <p>"I have felt coerced into returning to work before I was ready."</p> <p>"I wanted to work more during my cancer treatment, but was discouraged from doing so."</p>
Desire for concern by employer	Amir, 2008; Kennedy, 2006; Parsons, 2008	Compassion	"My supervisors/work partners are more concerned about my absences than about my health."
Desire for work-related support from family, friends, and coworkers	Main, 2005; Parsons, 2008		"My family, friends, and coworkers have been supportive of me as I have coped with distress related to changes in my work life."
Physical, emotional impairment (work barriers)	Costanzo (2009) Liu, (2007) Short (2004) Steiner (2008)	Accommodation; flexibility; job support	"My workplace has made adjustments or would make adjustments for my physical and emotional needs after cancer."
Discrimination	Amir, 2008 Parsons, 2008	Information, legal support	"I believe I have been discriminated against by my workplace because of my cancer."

Figure 5. Question development based on cancer patients' work-related statements, drawn from qualitative studies and personal observations of (by?)the author.

Appendix A

Items Included in Global Work-Related Distress Variable

1. I regret when I have to miss work, because work gives me a reason to get up in the morning and structures my day. (Item 44)
2. It doesn't bother me to miss work during cancer treatment; I would be happy never having to work in a full-time job again. (Item 46, reverse scored)
3. I wish I could work more to keep my mind off cancer. (Item 47)
4. If I can't work anymore, it means the cancer has defeated me. (Item 50)
5. I don't like to miss work due to my cancer because people my age should be working. (Item 51)
6. My supervisors/work partners are more concerned about my absences than about my health. (Item 52)
7. I miss working during cancer treatment because work gives meaning to my life. (Item 53)
8. There are people from work who I haven't told that I have cancer. (Item 54)
9. I have been disappointed by how some of my co-workers have reacted to my cancer. (Item 55)
10. I miss working because the life of a cancer patient is boring. (Item 56)
11. I don't miss my coworkers much when I cannot work; my closest friends aren't associated with my job. (Item 57, reverse scored)
12. When I can't work, I miss knowing what's going on in my coworkers' lives. (Item 58)
13. If I can't return to work, I'll really worry about my ability to pay bills and obtain health insurance. (Item 59)
14. My cancer diagnosis seemed to make some of my coworkers pull away from me. (Item 60)
15. I worry that my coworkers have to work harder because of my cancer-related absences. (Item 61)
16. I have felt lonely being away from work due to my illness. (Item 62)
17. I have more positive interactions with people at the Cancer Center than I did at work. (Item 64, reverse scored)
18. I miss work because working means I'm somebody. (Item 65)
19. I'm relieved to be away from the snobby "in-crowd" at work when I'm in treatment. (Item 66, reverse scored)
20. During treatment, I miss work because it is an important source of pride and satisfaction to me. (Item 67)

21. When I'm in treatment, I miss making important contributions at my workplace.
22. I don't worry about missing work. After I'm gone, people will remember me most for things that have nothing to do with my work. (Item 69, reverse scored)
23. Because of my cancer, I will have to work harder to achieve my career goals. (Item 70)
24. I have received plenty of information about cancer, sick leave, disability, and other benefits. (Item 71, reverse scored)
25. In a way, cancer was a blessing because it made me realize I was putting too much of my time and energy into work. (Item 72, reverse scored)
26. It helps me to think of cancer as my new job. (Item 73, reverse scored)
27. Cancer interrupted my work plans, but I have no regrets about that. (Item 74, reverse scored)
28. I still hear from some of my work friends, but I definitely feel out of the loop. (Item 75)
29. My doctor(s) and other health professionals were helpful in advising me about whether I should cut back on work, quit work, or go back to work. (Item 76, reverse scored)
30. I have felt coerced to return to work before I was ready. (Item 77)
31. I wanted to work more during cancer treatment, but was discouraged from doing so. (Item 78)
32. My family, friends, and coworkers have been supportive of me as I have coped with distress related to changes in my work life. (Item 79, reverse scored)
33. My workplace has made adjustments or would make adjustments for my physical and emotional needs after cancer. (Item 80, reverse scored)
34. I worry about not being able to work like I once did because of memory, concentration, and/or energy problems. (Item 81)
35. I worry about not being able to work like I once did because I haven't been able to keep up with the skills and changing challenges of the job world. (Item 82)
36. I believe that I have been discriminated against by my workplace because of my cancer. (Item 83)
37. My work friends have become even closer friends following my cancer diagnosis. (Item 85, reverse scored)

Appendix B

Items Included in Composite Sub-Categories of Distress

Structural

1. I regret when I have to miss work, because work gives me a reason to get up in the morning and structures my day.
2. When I am able to work, it makes me feel normal.
3. It doesn't bother me to miss work during cancer treatment; I would be happy never having to work in a full time job again. (Reverse scored)
4. Work gives me a reason to get up in the morning and structures my day.
5. I wish I could work more to keep my mind off cancer.
6. If I can't work anymore, it means the cancer has defeated me.
7. I don't like to miss work due to my cancer because people my age should be working.
8. I miss work because the life of a cancer patient is boring.
9. If I can't return to work, I'll really worry about my ability to pay bills and obtain health insurance.
10. It helps me to think of cancer as my new job. (Reverse scored)
11. I worry about not being able to work like I once did because of memory, concentration, and/or energy problems.
12. I worry about not being able to work like I once did because I haven't been able to keep up with the skills and changing challenges of the job world.

Social

1. There are people at work who I haven't told that I have cancer.
2. I have been disappointed by how some of my co-workers have reacted to my cancer.
3. I don't miss my coworkers much when I cannot work; my closest friends aren't associated with my job. (Reverse scored)
4. When I can't work, I miss knowing what's going on in my coworkers' lives.
5. My cancer diagnosis seemed to make some of my coworkers pull away from me.
6. I worry that my coworkers have to work harder because of my cancer-related absences.
7. I have felt lonely being away from work due to my illness.
8. I have more positive interactions with people at the Cancer Center than I did at work.
9. I'm relieved to be away from the snobby 'in-crowd' at work when I'm in treatment. (Reverse scored)
10. I still hear from some of my work friends, but I definitely feel out of the loop.
11. My work friends have become even closer friends following my cancer

diagnosis. (Reverse scored)

Existential

1. I miss working during cancer treatment because work gives meaning to my life.
2. I miss work because working means I'm somebody.
3. During treatment, I miss work because it is an important source of pride and satisfaction to me.
4. When I'm in treatment, I miss making important contributions at my workplace.
5. I don't worry about missing work. After I'm gone, people will remember me most for things that have nothing to do with my work.
6. Because of my cancer, I will have to work harder to achieve my career goals.
7. In a way, cancer was a blessing because it made me realize I was putting too much of my time and energy into work. (Reverse scored)
8. Cancer interrupted my work plans, but I have no regrets about that. (Reverse scored)

Lack of Work Related Support

1. My supervisors/work partners are more concerned about my absences than about my health.
2. I have received plenty of information about cancer, sick leave, disability, and my other benefits. (Reverse scored)
3. My doctor(s) and other health professionals were helpful in advising me about whether I should cut back on work, quit work, or go back to work. (Reverse scored)
4. I have felt coerced to return to work before I was ready.
5. I wanted to work more during cancer treatment, but was discouraged from doing so.
6. My family, friends, and coworkers have been supportive of me as I have coped with distress related to changes in my work life. (Reverse scored)
7. My workplace has made adjustments or would make adjustments for my physical and emotional needs after cancer. (Reverse scored)
8. I believe that I have been discriminated against by my workplace because of my cancer.

*Appendix C***Form A: Informed Consent.****Informed Consent Form: “Work and Cancer” Questionnaire**

Antioch University and the Cancer Center of Santa Barbara are committed to the ethical protection of participants in research. This form will provide you with information about the questionnaire that you are being asked to fill out so that you can decide whether you wish to participate. Participation in this survey is voluntary and anonymous. Your answers will be identified only by a code number, not by your name, and none of the physicians, nurses, or other health professionals at the Cancer Center of Santa Barbara will know whether or not you filled out the questionnaire.

This questionnaire is about cancer patients and their attitudes toward work, including feelings about any interruptions in work they may have experienced due to their cancer or cancer treatment. The questionnaire will likely take less than an hour to complete. You do not have to finish it all at one time, nor do you have to answer every question. If you decide to participate, we ask that you sign this form and include it in the envelope provided when you return your questionnaire. When the analysis of this study is complete (approximately Dec. 1, 2010), you will be provided with the overall results of the survey, and you will be free to ask any questions.

If you decide to participate, your answers may help medical professionals and employers understand more about how cancer impacts people and their feelings about themselves and their work. While it is highly unlikely, the possibility exists that answering questions about cancer and your work life may be upsetting, or raise uncomfortable issues for you. Be assured that if this happens, you may contact the study investigators with your concerns, and steps will be taken to

insure that you receive a list of local resources that can provide counseling and support to you.

If you have any further questions concerning this study please feel free to contact study investigator, Betsy Bates Freed, M.A., or her supervisor, Ryan Sharma, Psy.D., at Antioch University Santa Barbara, 801 Garden Street, Santa Barbara, California, 93101, (805) 962-8179. If you agree to the terms of this agreement, and wish to include your answers to the questionnaire in this study, please sign on the space below that you understand your rights and agree to participate in this study.

Your participation is invited, yet strictly voluntary. All information will be kept confidential and your name will not be associated with any research findings.

Signature of Participant

Betsy Bates Freed, M.A., Investigator
Antioch University Santa Barbara

Ryan Sharma, Psy.D., supervisor
Antioch University Santa Barbara

(Print name)

Appendix D
Form B

**Insuring Informed Consent of Participants in Research:
Questions to be answered by AUSB Researchers**

- 1. Are your proposed participants capable of giving informed consent? Are the persons in your research population in a free-choice situation?...or are they constrained by age or other factors that limit their capacity to choose? For example, are they adults, or students who might be beholden to the institution in which they are enrolled, or prisoners, or children, or mentally or emotionally disabled? How will they be recruited? Does the inducement to participate significantly reduce their ability to choose freely or not to participate?**

The participants in my study, adult cancer patients being treated at an independent, nonprofit cancer center, are capable of giving informed consent. The decision to fill out the questionnaire is completely voluntary, as will be explained in the accompanying documents. Patients will be selected via the Cancer Center of Santa Barbara database of consecutive patients treated, and sent a letter from the Cancer Center. The only identifying information on the questionnaire will be a code number and access to the codes will remain with the Cancer Center study coordinator. Although their physicians may sign a recruitment letter accompanying the questionnaire, their physicians will have no access to the codes that would indicate whether or not a certain patient had participated. There will be no inducement to participate other than the possibility of furthering research on the psychosocial needs of cancer patients like themselves, which is explained in the Informed Consent.

- 2. How are your participants to be involved in the study?**

The participants will fill out a questionnaire about their demographic information, cancer history, and attitudes about work and will return the survey and an informed consent agreement in a pre-addressed, stamped envelope to Antioch University Santa Barbara.

- 3. What are the potential risks – physical, psychological, social, legal, or other? If you feel your participants will experience “no known risks” of any kind, indicate why you believe this to be so. If your methods do create potential risks, say why other methods you have considered were rejected in favor of the method chosen.**

The only potential risk faced by participants in this study might be emotional discomfort associated with contemplating their cancer and the impact it may

have had on their work lives. This risk, I believe, is minimal. Still, referrals will be available for any patient who feels they might require counseling to aid in the processing of emotions that might arise as a result of completing the questionnaire. Specifically, contact information will be provided for the student investigator and dissertation chair. Both individuals will be prepared to facilitate community mental health referrals and links to no-cost Santa Barbara Cancer Center social services resources to any participant who expresses discomfort associated with participation in the study.

An alternative method of data collection would be face-to-face administration of the questions; however, this strategy would be less likely to preserve anonymity and might inadvertently exert social pressure on respondents to fill out the questionnaire and answer every question. A mailed questionnaire would be easier to simply ignore, should a patient feel some level of anxiety about the subject matter or simply lack the energy or motivation to participate. Finally, the mailed version would permit cancer patients to complete it in a comfortable setting when they feel up to the task.

4. What procedures, including procedures to safeguard confidentiality, are you using to protect against or minimize potential risks, and how will you assess the effectiveness of those procedures?

Cancer patients' addresses will be accessed, and letters sent, by the research division at the Cancer Center of Santa Barbara, which maintains strict confidentiality of patient records in accordance with the patient privacy act, HIPAA (Health Insurance Portability and Accountability Act.) The only identifying piece of information on each questionnaire will be a code number, which will be linked to a patient name only through the Cancer Center of Santa Barbara research division, which has multi-level data security safeguards in place compatible with federally funded research routinely completed at the facility. All completed questionnaires will be sent to Antioch University, where they will be secured during processing and the compilation of data. Upon completion of data collection, these records will be kept in a secured location for a period of 5 years, at which time they will be shredded.

5. Have you obtained (or will you obtain) consent from your participants in writing? (Attach a copy of the form.)

Each participant will be asked to sign an informed consent document within a packet of materials that also contains contact information for the student investigator and the dissertation chair. Envelopes missing signed informed consent forms will not be included in data collection and will be shredded; however, all participants who received the materials will have access to

referrals should they experience any distress associated with receipt of the materials or other levels of study participation.

6. What are the benefits to society, and to your participants, that will accrue from your investigation?

Qualitative studies exploring psychosocial distress in cancer patients frequently elicit responses that suggest that losses associated with work are profound and generally not addressed by health care professionals or employers. This study could be the first step in identifying particular aspects of job interruption that interfere with adjustment to cancer, perhaps leading the way to an instrument that could assess job-related distress and alert health care professionals, employers, and mental health care providers to the need for counseling, guidance, and support in this area. Participants who complete the questionnaire may obtain some altruistic personal benefit in feeling that they are contributing to a better understanding of sources of distress among cancer patients, and thus might be helping in the care of future patients like themselves.

7. Do you judge that the benefits justify the risks in your proposed research? Indicate why.

I believe that the risks associated with participation in this survey are minimal and clearly are outweighed by potential benefits to society associated with enhancing understanding of an a poorly understood source of distress in cancer treatment and recovery.

Both the student and her Dissertation Chair must sign this form and submit it before any research begins. Signatures indicate that, after considering the questions above, both student and faculty person believe that the conditions necessary for informed consent have been satisfied.

Date: _____

Signed: _____

Student

Date: _____

Signed: _____

Dissertation Chair

Appendix E
Demographic Frequencies

		Age			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	26-35	1	1.3	1.4	1.4
	36-45	3	4.0	4.1	5.5
	46-55	14	18.7	19.2	24.7
	56-65	19	25.3	26.0	50.7
	66-75	20	26.7	27.4	78.1
	Over75	16	21.3	21.9	100.0
	Total	73	97.3	100.0	
Missing	System	2	2.7		
Total		75	100.0		

		Sex			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	28	37.3	38.4	38.4
	Female	45	60.0	61.6	100.0
	Total	73	97.3	100.0	
Missing	System	2	2.7		
Total		75	100.0		

Education

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than High School	1	1.3	1.4	1.4
	High School	3	4.0	4.2	5.6
	Graduated High School	5	6.7	7.0	12.7
	Some College	21	28.0	29.6	42.3
	Graduated College	16	21.3	22.5	64.8
	Some Post-Grad	9	12.0	12.7	77.5
	Post-Graduate degree	16	21.3	22.5	100.0
	Total	71	94.7	100.0	
Missing	System	4	5.3		
Total		75	100.0		

Professional/employment Category

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Labor/manufacturing	4	5.3	6.2	6.2
	Skilled technical, clinical/service	13	17.3	20.0	26.2
	Exec/managerial/prof.	48	64.0	73.8	100.0
	Total	65	86.7	100.0	
Missing	System	10	13.3		
Total		75	100.0		

Personal Income in Year Prior to Diagnosis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than \$25,000	20	26.7	30.8	30.8
	\$25,000-\$50,000	20	26.7	30.8	61.5
	\$50,000-\$75,000	12	16.0	18.5	80.0
	\$75,000-\$100,000	5	6.7	7.7	87.7
	More than \$100,000	8	10.7	12.3	100.0
	Total	65	86.7	100.0	
Missing	System	10	13.3		
Total		75	100.0		

Personal Income During 2009

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than \$25,000	21	28.0	32.3	32.3
	\$25,000-\$50,000	20	26.7	30.8	63.1
	\$50,000-\$75,000	11	14.7	16.9	80.0
	\$75,000-\$100,000	4	5.3	6.2	86.2
	More than \$100,000	9	12.0	13.8	100.0
	Total	65	86.7	100.0	
Missing	System	10	13.3		
Total		75	100.0		

Household Income Prior to Cancer Diagnosis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than \$25,000	9	12.0	14.1	14.1
	\$25,000-\$50,000	20	26.7	31.3	45.3
	\$50,000-\$75,000	8	10.7	12.5	57.8
	\$75,000-\$100,000	9	12.0	14.1	71.9
	More than \$100,000	18	24.0	28.1	100.0
	Total	64	85.3	100.0	
Missing	System	11	14.7		
Total		75	100.0		

Household Income During 2009

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than \$25,000	13	17.3	20.3	20.3
	\$25,000-\$50,000	19	25.3	29.7	50.0
	\$50,000-\$75,000	7	9.3	10.9	60.9
	\$75,000-\$100,000	7	9.3	10.9	71.9
	More than \$100,000	18	24.0	28.1	100.0
	Total	64	85.3	100.0	
Missing	System	11	14.7		
Total		75	100.0		

Cancer Type					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Breast	36	48.0	50.0	50.0
	Prostate	11	14.7	15.3	65.3
	Other	25	33.3	34.7	100.0
	Total	72	96.0	100.0	
Missing	System	3	4.0		
Total		75	100.0		

Cancer Stage					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I	18	24.0	40.9	40.9
	II	8	10.7	18.2	59.1
	III	9	12.0	20.5	79.5
	IV	9	12.0	20.5	100.0
	Total	44	58.7	100.0	
Missing	System	31	41.3		
Total		75	100.0		

Presence/absence of Recurrence					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	56	74.7	75.7	75.7
	Yes	18	24.0	24.3	100.0
	Total	74	98.7	100.0	
Missing	System	1	1.3		
Total		75	100.0		

ECOG Performance Status (Physical function)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Active, fully able to work	40	53.3	56.3	56.3
	Restricted, light work	22	29.3	31.0	87.3
	Ambulatory, no work	6	8.0	8.5	95.8
	Limited self care	3	4.0	4.2	100.0
	Total	71	94.7	100.0	
Missing	System	4	5.3		
Total		75	100.0		

Work Orientation Scale: How Subjects View Their Work

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Job	23	30.7	37.7	37.7
	Career	11	14.7	18.0	55.7
	Calling	27	36.0	44.3	100.0
	Total	61	81.3	100.0	
Missing	System	14	18.7		
Total		75	100.0		

Current Work Status

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Part-time	14	18.7	19.4	19.4
	Full-time	17	22.7	23.6	43.1
	Homemaker	4	5.3	5.6	48.6
	Volunteer	3	4.0	4.2	52.8
	Retired	24	32.0	33.3	86.1
	Not working	10	13.3	13.9	100.0
	Total	72	96.0	100.0	
Missing	System	3	4.0		
Total		75	100.0		

Prior work status

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Part-time	17	22.7	23.6	23.6
	Full-time	26	34.7	36.1	59.7
	Homemaker	3	4.0	4.2	63.9
	Volunteer	3	4.0	4.2	68.1
	Retired	21	28.0	29.2	97.2
	Not working	2	2.7	2.8	100.0
	Total	72	96.0	100.0	
Missing	System	3	4.0		
Total		75	100.0		

Preferred Work Status

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Part-time	20	26.7	29.0	29.0
	Full-time	21	28.0	30.4	59.4
	Homemaker	3	4.0	4.3	63.8
	Volunteer	6	8.0	8.7	72.5
	Retired	18	24.0	26.1	98.6
	Not working	1	1.3	1.4	100.0
	Total	69	92.0	100.0	
Missing	System	6	8.0		
Total		75	100.0		

Work Status Loss Post-Cancer (i.e., Part Time from Full Time)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No Loss	52	69.3	77.6	77.6
	Loss	15	20.0	22.4	100.0
	Total	67	89.3	100.0	
Missing	System	8	10.7		
Total		75	100.0		

Considered Changing Jobs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	13	17.3	23.2	23.2
	No	43	57.3	76.8	100.0
	Total	56	74.7	100.0	
Missing	System	19	25.3		
Total		75	100.0		

Preferred Work versus Current Work

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Working as preferred	49	65.3	71.0	71.0
	Not working as preferred	20	26.7	29.0	100.0
	Total	69	92.0	100.0	
Missing	System	6	8.0		
Total		75	100.0		



Work and Cancer Questionnaire

Please answer these questions as best you can by filling in the blank, circling the answer that best fits your situation, or checking the most appropriate box. Remember, filling out this questionnaire is entirely voluntary and your answers will be kept confidential. You do not have to answer every question. Thank you so much for helping us to learn more about cancer and work.

Age: ☐ under 25 ☐ 26-35 ☐ 36-45 ☐ 46-55 ☐ 56-65 ☐ 66-75 ☐ over 75

Sex: ☐ Male ☐ Female

Highest Educational level obtained (choose one):

- ☐ Less than High School ☐ High School ☐ Graduated High School ☐ Some College
☐ Graduated from College ☐ Some Post-Graduate Work ☐ Post-Graduate Degree

Profession and employment category (choose one):

- ☐ Labor/manufacturing ☐ Skilled technical/clerical/service ☐ Executive/managerial/professional

Please indicate your *personal* income (not household income) in the year *prior* to your cancer diagnosis:

- ☐ Less than \$25,000 ☐ \$25,000 to \$50,000 ☐ \$50,000 to \$75,000
☐ \$75,000 to \$100,000 ☐ More than \$100,000

Please indicate your *personal* income during 2009: (This figure may be the same, depending on your date of diagnosis)

- ☐ Less than \$25,000 ☐ \$25,000 to \$50,000 ☐ \$50,000 to \$75,000
☐ \$75,000 to \$100,000 ☐ More than \$100,000

Please indicate your *household* income in the year *prior* to your cancer diagnosis:

- ☐ Less than \$25,000 ☐ \$25,000 to \$50,000 ☐ \$50,000 to \$75,000
☐ \$75,000 to \$100,000 ☐ More than \$100,000

Please indicate your *household* income during 2009: (This figure may be the same, depending on your date of diagnosis)

- ☐ Less than \$25,000 ☐ \$25,000 to \$50,000 ☐ \$50,000 to \$75,000
☐ \$75,000 to \$100,000 ☐ More than \$100,000

Type of Cancer: _____

Stage: _____

Date of initial cancer diagnosis: _____

Date of diagnosis of recurrence(s), if applicable: _____

Cancer made me consider changing jobs: ☐ Yes ☐ No

If yes, please check *all* that apply:

- ☐ For more money/better benefits
- ☐ For personal satisfaction
- ☐ To a less stressful job (or retirement)
- ☐ Because I could not perform my previous job
- ☐ Because I lost my job

Please use the following space (and additional paper, if desired) to offer your thoughts and insight on how your cancer has impacted your professional life and the role that work plays in your life.

Is there anything else you would like other cancer patients or physicians/nurses/employees/coworkers to know about cancer and work?
